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The experiences and support needs of people affected by cancer

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This thesis is submitted in partial fulfilment of the requirements for the degree of
Doctorate in Clinical Psychology

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List of abbreviations

CASP	Critical Appraisal Skills Program
CNS	Clinical Nurse Specialist
COSIP	Children of Somatically Ill Parents
CRUK	Cancer Research UK
DoH	Department of Health
IPA	Interpretative Phenomenological Analysis
MDT	Multidisciplinary Team
NICE	National Institute for Health and Clinical Excellence
RCT	Randomised Controlled Trial
SURE	Support Unit for Research Evidence
UK	United Kingdom
U.S.	United States of America

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Declaration

This thesis is an original piece of my own work, conducted under the supervision of Dr Eve Knight, Dr Carolyn Gordon and Dr Kate Martin. It has not as an entirety, or any part of it, been submitted for any other degree or to any other institution.

Chapters one and two of this thesis have been prepared for submission to the Journal of Psychosocial Oncology under the authorship of myself and the three research supervisors detailed above.

Summary

This thesis is an exploration of the experiences and support needs of people who are affected by cancer. It begins with a systematic review of interventions that are designed to support children who have a parent with cancer. Critical consideration of the value of these interventions in providing desired outcomes for the child and their family is the focus of this paper. Ten evaluations, consisting of nine separate interventions were included for review. Support for the efficacy of these interventions in providing improvements across a variety of outcomes concerning child well-being, parental well-being and overall family functioning is indicated. However, these findings must be considered within the context of the methodological limitations of the current research body. Clinical implications with regard to United Kingdom service provision and intervention planning are discussed.

The second paper reports on an Interpretative Phenomenological Analysis study exploring the experiences of people who have had a diagnosis of, and treatment for, malignant melanoma. Six participants were recruited to this study and interviewed using semi-structured interviews. Three overarching themes emerged from the data detailing the lived experiences for these participants. A tension between whether having melanoma was a serious life event or not, finding balance and dealing with the experience and reflections on the ongoing impact upon self typified these participants' experiences. These findings are discussed with regard to the implications for clinicians working with people who have been diagnosed with, and treated for, melanoma.

The final paper is a reflective account of the researcher's research journey. Specific focus is afforded to the development of the researcher's relationship with the topic area and the integral role of the participant interview process within this. The influence of the research experience in shaping the researcher's identity as a clinician is also considered, as are indications for ongoing development.

Overall word count = 18,208

Chapter 1: Literature Review

A critical review of interventions to support children who have a parent with cancer: Outcomes for children and their families.

In preparation for submission to the *Journal of Psychosocial Oncology* (See Appendix A for author instructions for submission)

Overall chapter word count (excluding tables, figure and references): 7617

1.1. Abstract

Aims: When a parent is diagnosed with cancer this can affect the well-being of the whole family. This systematic review was conducted to critically review evaluations of interventions designed to support children who have a parent with cancer. The review focusses specifically on outcomes for children and their families.

Method: PsycINFO, Medline, CINAHL and Web of Science were searched for articles published from 2004. Reference and citation searches were also conducted. A total of ten papers met the inclusion criteria.

Results: Positive outcomes with regard to a range of emotional well-being factors for children and parents, as well as improvements in general family functioning were reported. Findings are mixed, and are considered within the context of methodological limitations.

Conclusions: This review indicates the clinical utility of interventions designed to support children who have a parent with cancer. However, there is an absence of well-controlled, large scale evaluations affecting the overall quality of this body of research. Implications for clinicians and service provision are discussed.

Keywords: *parental cancer, oncology, family, children, intervention, support, well-being*

1.2. Introduction

A cancer diagnosis can involve a wide range of emotional, psychological and behavioural responses and affect many aspects of an individual's life. When it is a parent that is diagnosed with cancer this diagnosis can impact upon the whole family (Kissane *et al.* 1994). More than 300,000 people were diagnosed with cancer in the UK in 2011 (Cancer Research UK, 2014). Around 11% were aged between 15 and 49, the age group for which parenting a minor child is most probable. Statistics for the number of children affected by parental cancer is not available in the UK. However 18% of newly diagnosed cancer survivors in the U.S. reported living with a minor child (Weaver, Rowland, Alfano & McNeel, 2010). There were two million cancer survivors in the UK in 2008 (Maddams *et al.*, 2009). This is anticipated to increase by one million per decade (Maddams, Utley, & Møller, 2012). This indicates an even greater number of children who have had, or currently have, a parent with cancer.

1.2.1. Impact of parental cancer on children

How, and to what extent having a parent with cancer affects the child varies widely (Visser *et al.*, 2004). However, effects upon mood, self-esteem, cognitive and social changes have been described (Su & Ryan-Wenger, 2007). Many studies indicate the presence of psychological distress (e.g. depression and anxiety) for these children (e.g. Harris & Zakowski, 2003; Heiney *et al.*, 1997; Huizinga *et al.*, 2011; Nelson & While, 2001). Adolescents may be more susceptible to adverse emotional consequences than younger children (Grabiak, Bender & Puskar, 2007; Visser *et al.*, 2004). More sophisticated cognitive skills and an awareness of the connotations of

the situation (Compas *et al.*, 1994), as well as increased responsibilities placed upon them may account for this (Visser *et al.*, 2004). Adolescent daughters of ill mothers have been indicated to be the most susceptible to emotional problems (Visser *et al.*, 2004).

Osborn (2007) concludes from her systematic review of quantitative studies that overall, children do not have serious psychosocial difficulties as a result of having a parent with cancer. This finding may be influenced however, by the use of measures of psychopathology in these research studies. Such measures may not be sensitive to sub-clinical levels of distress, or other important concerns. Huang, O'Connor and Lee (2014) conducted a meta-synthesis of 24 qualitative studies focussed on the experiences of children and adolescents when a parent has cancer. A wide range of emotional concerns and reactions emerged, for children of all ages. This supports the proposition that parental cancer affects the emotional well-being of their children. Methodological differences may, in part, account for differences reported about the impact of cancer upon children's emotional well-being. Other social and contextual factors are also likely to be mediators, including the role of parents, available support, information provision and communication.

1.2.2. Parental well-being and the parent-child relationship

Parental well-being, adjustment and the parent-child relationship are all implicated in predicting a child's adaptation to having a parent with cancer (Krattenmacher *et al.*, 2012; Nelson & While, 2001). Chen *et al.* (2009) report their findings that 25% of cancer patients suffer from depression, and parental depression indicates poorer

adjustment in their children (Krattenmacher *et al.*, 2012). Visser *et al.* (2004) conclude from their systematic review that most studies indicate a positive association between the psychological functioning of the parent and the child. Even in the absence of mental ill-health, parental cancer may disrupt the parent's ability to parent by restricting their emotional or physical availability and therefore result in less positive outcomes for the child (Lewis, 1999). Parental difficulty with their own adjustment may too affect the child's adjustment (Nelson & While, 2001; Kennedy & Lloyd Williams, 2009).

Adolescent perception of the strength of their relationship with a parent, and a continuation of the existing relationship dynamic has found to be a protective factor against anxiety in adolescents, and to facilitate coping when faced with parental cancer (Barnes *et al.*, 2000; Maynard, 2013). This is particularly the case if the relationship was positive prior to diagnosis (Christ, Siegel, & Sperber, 1994).

1.2.3. Supporting children: The importance of information and communication

The adjustment of children and adolescents to the difficulties of having a parent with cancer can be improved by the provision of timely, developmentally appropriate and well communicated information (Barnes *et al.*, 2000; Forrest *et al.*, 2006; Maynard, 2013). This may relate to decreased levels of anxiety in children (Watson *et al.* 2006). Seeking factual information emerged as a core theme for children within qualitative studies (Huang *et al.*, 2014) and this is sought from a variety of sources (Kristjanson, Chalmers & Woodgate 2004; Maynard, 2003). Parents are often the main source for information, particularly if they are open in their communication (Huang *et al.*, 2014).

Healthcare professionals and schools can also play an important role in providing children with information and support, particularly when this is communication at a level appropriate to the child or adolescent's age and needs (Kennedy & Lloyd-Williams, 2009; Kristjanson *et al.*, 2004). Children and adolescents also value the opportunity to speak with someone outside of the family, whom they perceive to be understanding (Kennedy & Lloyd-Williams, 2009).

1.2.4. Structured child-centred interventions

Niemelä, Hakko and Räsänen (2010) conducted a systematic review of structured child-centred interventions for families with a parent who has cancer. Eleven intervention studies published up until 2007 were elicited from the search. Five of these studies did not, however, report outcomes for families. Where these outcomes were provided, clear criticisms exist regarding the methodological rigour of the evaluations and the quality of the outcome reporting. Of the six studies which do provide outcomes for children and their families, three of these comprise qualitative data derived without clear methodologies or analysis. As an assessment of the quality and rigour of studies was not integral to this systematic review, these, and other potential sources of bias are not clear. A review of psycho-social interventions for children with a parent receiving palliative care (Kuhne *et al.*, 2012) included two studies which were specifically for children with a parent with terminal cancer.

Over the last decade there has been increased emphasis on the psychological needs and psycho-social support provision for this population, although it remains an under-studied and under-supported group when compared to other groups affected

by cancer (e.g. patients with cancer diagnoses, parents of children with cancer). With the number of children affected by having a parent with cancer projected to increase further, and indications from multiple sources about the potential for a negative impact upon children's well-being, it remains an important area for research. The Children of Somatically Ill Parents (COSIP) group is a multi-national project commissioned by the European Commission to further investigate this population and interventions that can be employed to support them.

1.2.5. Rationale for and aims of the current review

The current review aims to build upon the Niemelä *et al.* (2010) review by systematically reviewing and critiquing evaluations of interventions designed to support children who have a parent with cancer. This review will focus on the outcomes of these interventions for children and their families. This is specifically important in considering the efficacy and utility of any intervention and can assist with ongoing service and intervention development (Campbell *et al.*, 2007). This review will seek to critically analyse intervention evaluations published only in the last decade, since 2004. This is to ensure the research is up-to-date and relevant and therefore best positioned to inform current practice. It is anticipated that this review will be able to offer an overview of interventions currently employed to support this population as well as a critical consideration of the value of these interventions in providing desired outcomes for the children and their families. The implications of the findings for professionals working with parents with cancer and/or their children will be considered.

1.3. Method

1.3.1 Search strategy

Search terms were selected based upon meeting the aims of the literature review; to critically evaluate interventions to support children who have a parent with cancer. As preliminary searches revealed relevant papers, keywords were noted and used to inform the final search terms. Synonyms were used to try to ensure breadth of coverage of the search. Table 1, indicates the search terms used, where the Boolean operator “AND” was utilised so that results included terms from each of the four indicated searches.

Table 1.1. Search terms used

Search 1	Search 2	Search 3	Search 4
A parent	With cancer	A child	Intervention
Parent*	Cancer	Child*	Intervention
Mother	Oncolog*	Adolescen*	Support
Father			Therap*
			Counsel*

Databases were selected to best meet the requirements for this literature review. Abstract searches of PsycINFO, Medline and CINAHL (accessed through the EBSCO platform) and a title search of Web of Science was conducted in April 2014. This was supplemented with reference and cited searches of relevant papers from the search, as well as core subject articles.

1.3.2 Selection criteria

Studies were selected for inclusion in the study by pre-determined inclusion and exclusion criteria.

1.3.2.1 Inclusion criteria

Studies were included if they i) were published in a peer reviewed journal, ii) involved an evaluation of an intervention designed to support children who have a parent with cancer, iii) reported outcomes for children and/or their families following the implementation of the intervention, iv) published since 2004.

1.3.2.2 Exclusion criteria

Studies were excluded if i) the paper was a review, book chapter, editorial, commentary, poster publication or meeting abstract, ii) the paper concerned adults who had a parent with cancer, iii) the full text was not published in English.

1.3.3. Systematic search results

Database searches as detailed above returned 659 potential articles. These were reviewed by title and abstract resulting in the exclusion of 631 articles. The full text versions of the remaining 28 papers were then reviewed. Eight articles met the criteria for inclusion. A further two research articles were identified through reference and cited searches, resulting in a final ten research articles for inclusion in the review. Figure 1., over, details this process including details of exclusion at each stage.

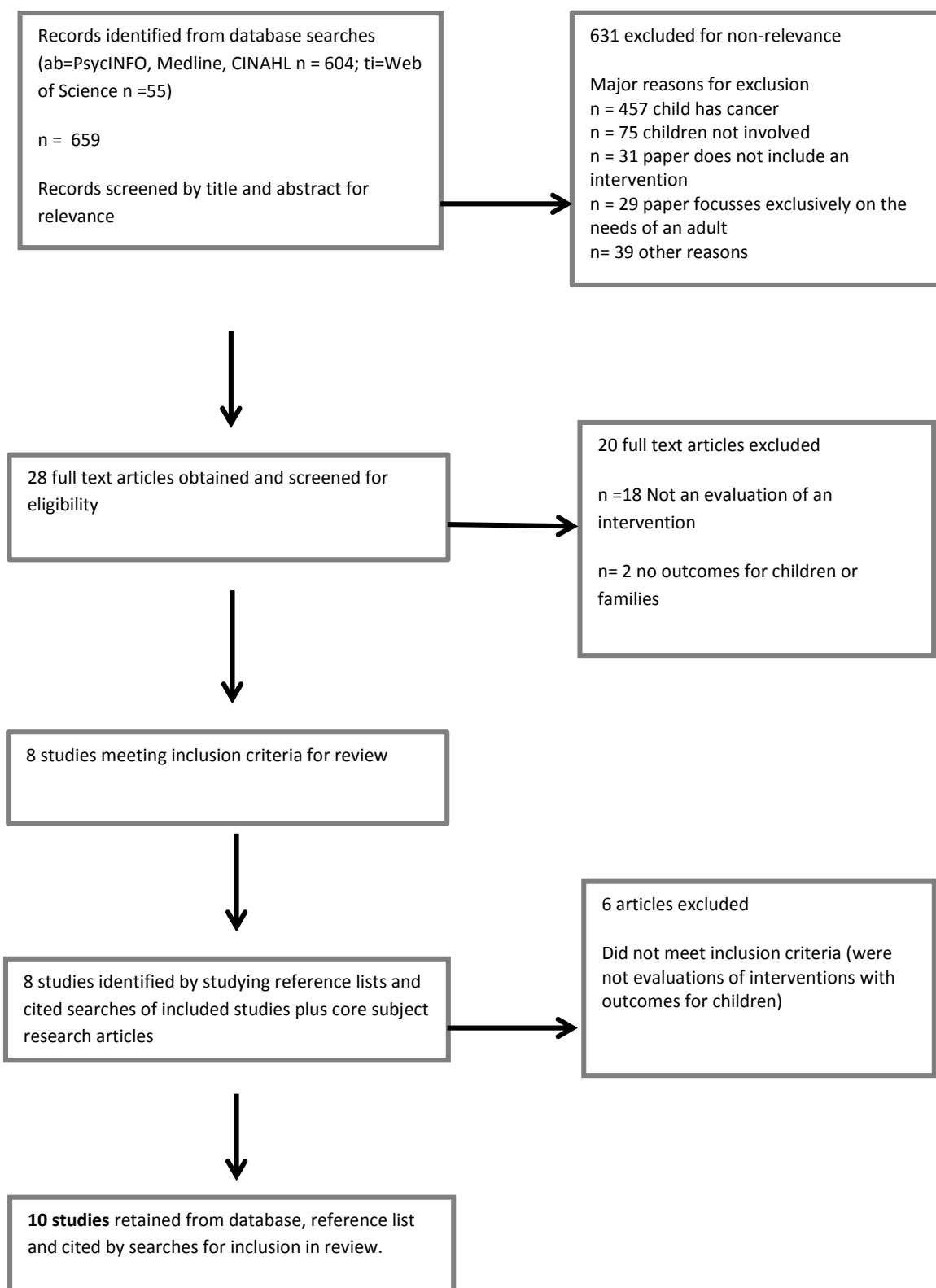


Figure 1. Systematic search strategy

1.3.4 Study quality assessment

Following identification of studies for inclusion, an assessment of the study quality was conducted. Quality assessment checklists specifically designed to aid the critical evaluation and assessment of validity of intervention studies were consulted (e.g. Critical Appraisal Skills Program (CASP), 2013; Downs & Black, 1998; Support Unit for Research Evidence (SURE), 2013; Yates *et al.*, 2005). The National Institute for Health and Care Excellence (NICE, 2012) Quality Appraisal Checklists for quantitative and qualitative intervention studies were selected for quality assessment procedures in the review, as they best encapsulated the review's critique requirements. Two questions were adapted in line with Downs and Black's (1998) checklist, for question clarity. Non-relevant questions were excluded and items specifically concerned with intervention quality were incorporated from Yates *et al.*'s (2005) quality checklist. Two final checklists, one for quantitative studies, and one for qualitative studies were used within this review (Appendix B). Those using mixed methodologies were assessed using both checklists.

Studies were assessed against these checklists and scores given for compliance with each criteria. Two points were awarded where a study fully met the criteria, one for partial adherence, and zero where the study did not fulfil the criteria. Where compliance was unclear or not applicable this was noted. These scores were combined and converted to percentages for an overall quality assessment score. These are included in table 1.2, below, in the results section, for each study.

1.4. Results

1.4.1. Findings overview

The systematic search strategy detailed above resulted in ten research papers meeting the inclusion criteria for review. These studies all comprise an evaluation of an intervention designed to support children who have a parent with cancer. See table 1.2, over for details of these studies.

These ten studies evaluated nine different interventions (Bugge, Helseth & Darbyshire, 2008 and Bugge, Helseth & Darbyshire, 2009, are both evaluations of the “Family Talks in Cancer Care” intervention with differing evaluation focuses). Two of the interventions focussed specifically on mothers with breast cancer and their children (John, Baker & Mattejat, 2013; Lewis, Casey, Brandt, Shands & Zahlis, 2006). Three were specifically for children whose parent had incurable cancer (Bugge *et al.*, 2008; Bugge *et al.*, 2009; Kenendy, McIntyre, Worth & Hogg, 2008). Three studies were conducted in the USA, five in Europe and two in the UK.

Three of the studies reviewed utilised quantitative methodologies (Davey, Kissil, Lynch, Harman & Hodgson, 2013; John *et al.*, 2013; Niemelä, Repo, Wahlberg, Hakko & Räsänen, 2012). Five interventions were evaluated qualitatively (Bugge *et al.*, 2008; Bugge *et al.*, 2009; Kennedy *et al.*, 2008; Semple & McCaughan, 2013; Tucker Sugerman & Zelov, 2013) and two used mixed methods (Thastum *et al.*, 2006; Lewis *et al.*, 2006). The interventions focussed either on supporting children only or children within the context of their families, and varied in terms of their specific aims,

and the outcomes they measured. The content and delivery of interventions and the context and settings within which they were delivered also differed (including within the community and inpatient hospital environments). Quality ratings for studies varied with qualitative methodology studies scoring higher, overall, than quantitative studies. Findings, including critical analysis of the evaluations, are discussed below, beginning with child only interventions before moving on to those that are family focussed.

Table 1.2. Descriptions of reviewed studies

Study details	Intervention	Theoretical background of intervention	Intervention aims	Description of intervention	Study method and sample	Data Analysis	Main findings
Bugge, Helseth & Darbyshire (2008) Norway Quality Score: 70%	'Family Talks in Cancer Care' (Family Support Program)	Coping Theory for Children Family Resilience Theory	Prevent psychosocial problems and promote coping in children 1.Help the family to talk about the illness 2.Provide children with knowledge and security 3.Help the family plan for the future	Four meetings over six weeks (plus one 'after death') Manualised programme. Programme includes how to increase communication within the family and improve the children's understanding. Various strategies employed (e.g. books, films, drawing)	Qualitative methodology. Interviews N = 12 children, aged 6-16, (mean age 9); (8 girls, 4 boys)	Qualitative analysis according to Kvale (1996)	1. Support to talk to parents 2. Benefits of talking with parents as well as on their own 3. Increasing knowledge 4. Learning about how to cope with emotions
Bugge, Helseth & Darbyshire (2009) Norway Quality Score: 70%	'Family Talks in Cancer Care' (Family Support Program)	Coping Theory for Children Family Resilience Theory	To help parents meet challenges regarding their children 1.Help the family to talk about the illness 2.Help parents understand child needs 3.Help family plan for future	Four meetings over six weeks (plus one 'after death') Manualised programme. Programme includes how to increase communication within the family and improve the children's understanding. Various strategies employed (e.g. books, films, drawing)	Qualitative methodology. Interviews N = 13 parents (6 cancer patients)	Qualitative analysis according to Kvale (1996)	1. Support of open communication 2. Support to understand children 3. Feelings of confirmation 4. Support to deal with own feelings and thoughts

Davey, Kissil, Lynch, Harman & Hodgson (2013) USA Quality Score: 57%	Culturally adapted family intervention	Attachment theory	Focus on improving parent-child attachment and communication	Five, bi-monthly support group sessions. Three group sessions with children only focussing on: 1. Building empathy and understanding 2. Improving coping 3. Open communication of thoughts and feelings Two group family sessions, focussing on: 1. Encouraging faith, spirituality and using the African American community 2. Promoting secure attachment and open communication	Pilot study Pre and post intervention measurements. Measures: family interaction (IBQ) child's depression (CDI), child's anxiety (RCMAS), maternal depression (CES-D) Nonrandomised control group design: N = 7 African American Families (treatment group) N = 5 Control group (usual psych-ed group) African American families. Children aged 10-18 (mean=16)	Statistical comparison of pre and post scores on measures	Communication with children improved following the intervention for parents in the treatment condition No significant improvements in parent or child depression, child anxiety or views on the parental-child relationship Greater satisfaction reported for the treatment group than the control group
John, Becker & Mattejat (2013) Germany Quality Score: 40%	"Getting well together" In-patient programme	Resource-oriented positive psychology, stress and coping research, systemic solution focussed therapy	Prevent of serious emotional and behavioural problems as a consequence of the child's mother having cancer	3 week residential inpatient programme Manualised programme Child-centred group interventions, high quality child care, oncology components and at least two counselling sessions. Groups included three sessions with children (develop coping strategies, facilitate communication of emotion, promoting strengths); 2 sessions for mothers (communication within the family)	Pilot study Within- subject control group design Pre 1 , pre 2 and post intervention measures Measures used: Mother's QoL (EORTC QLQ-C30); Child's QoL (ILC); Child's psychopathological symptoms (SDQ) N = 116 women with breast cancer and their eldest child (child aged from 3-14, mean 7.4)	Statistical comparison of measure scores: Sample group compared to 'norm' population Pre-1 to Pre-2 (waiting period) Pre-2 – Post (intervention)	Significant improvement on: mother's emotional functioning, children's psychological health and emotional symptoms

Kennedy, McIntyre, Worth & Hogg (2008)	Support service for families where a parent is dying from cancer	Not known	Not clear	Community based service. Trained Family Support Workers supporting children and families	Qualitative methodology. Purposive sample of 6 families Interview after referral and then after 3 months & 5 sessions. Plus interviews with family support worker	Qualitative analysis supported by NVivo analysis software	Intervention as holding families steady and supporting journeying together Families valued the service and highly endorsed it
UK							
Quality score:							
50%							
Lewis, Casey, Brandt, Shands & Zahlis (2006)	The Enhancing Connections Program	Cognitive-behavioural, social cognitive theory, developmental-contextual model of parenting, coping theory	To reduce cancer related distress and co-morbidity	Scripted intervention 5 x 1 hour sessions Consisting of: 5 scripted patient education sessions for mother Interactive educative booklet for mother to read to child Homework workbook for mother Child's "my story" book Access to patient educator	Pilot study Within-subject, pre and post design Standardised measures Key measures: mother's mood and anxiety (CES-D, STAI); maternal self-efficacy (CASE); mother-child relationship (FPRQ); child's cancer related concerns; child's anxiety (RCMAS); child's depression (CDI) and CBCL N =13 mothers with breast cancer and child(ren) aged between 8 and 12	Statistical comparison of mother, father and child pre and post measures scores Qualitative analysis of mothers' written feedback	Child: Decrease in the child's cancer related worries and improvement in their emotional-behavioural functioning Parent: Improvement on mother's depression, anxiety and self efficacy ratings Mothers reported improved efficacy in managing their emotions with the child, own self-care, better ability to listen to and understand their child
USA							
Quality Score:							
40% (quantitative)							
70% (qualitative)							

Niemela, Repo, Wahlberg, Hakko & Rasanen	The Struggle for Life: A Preventative Intervention.	Based upon interventions developed to help children with a parent with a mood disorder	Unclear	LTC: Two psycho-educational sessions with parents only FT: 6-8 sessions with family. 2 sessions with parents only, Individual session with child. Full family sessions to discuss topics important to the family	Pilot study Within-subject, pre and post design Measure of parental psychiatric symptoms (SCL-90) N = 19 families, n= 10 completed follow up	Statistical comparison of pre and post measures. Comparison to general population	Decrease in parental level of psychopathology after intervention. Decrease in psychiatric symptoms to equal to general population
2012	Including						
Finland	Let's Talk about the Children intervention (LTC)						
Quality Score:	The Family Talk Intervention (FT)						
37%							
Semple & McCaughan,	CLIMB® – psychosocial intervention	Behaviour as a function of social context	1. Education about cancer 2. Normalise emotions 3. Support communication of emotions 4 Improve coping	6 week group intervention Children aged 5-12 Learning about cancer and to express emotions through play and art	Focus groups – N = 7 children (aged 6-11) N = 6 parents Interviews with two of the facilitators	Qualitative analysis – Thematic analysis	Parents: Children demonstrating more adaptive coping strategies Improvements in child mood and behaviour. Liked the ad hoc support they gained from other parents Children: Peer support, normalising of experience 'Safe' Space Clarification of misconceptions Forum to explore their own emotions
2013							
N.Ireland							
Quality Score:							
85%							

Thastum. Munch- Hansen, Wiell & Romer	Short term preventative counselling for families	Not known	To support the family in taking care of the children's needs. Intervention upon family systems, at a parental level and child level	Focussed, needs based, short term counselling. Maximum 5-6 sessions focussed on illness related concerns	Between-subject control group design Pre and post intervention standardised measures. Key measures: Parental mood (BDI); family relating (McMaster FAD); Child anxiety, depression and self-efficacy (subscales from BYI) N = 21 families (including 34 children) Control group: n = 16 families Semi-structured interview with families and counsellors	Quantitative analysis: Pre and Post comparison of standardized measures: parents and children Qualitative analysis: Phenomenological method combined with elements of grounded theory.	Children: Decrease in depression. No sig. impact upon anxiety. Parents: Depression decreased. Communication, affective responsiveness and general family functioning showed significant improvement Qualitative analysis: Improved understanding of emotions and each other; increased intimacy and cohesion, increased normalisation and legitimacy of feelings.
2006							
Denmark							
Quality Score:							
40% (quantitative)							
75% (qualitative)							
Tucker, Sugerman & Zelov	"On Belay"	Not known	Building community among children who have a family member with cancer. Help youths discover their personal power within coping.	One day outdoor adventure programme. Cooperative games, problem- solving.	Focus group Children and their parents who have attended programme at least twice in three years N = 12 youths, aged 10-15 N = 9 parents	Qualitative analysis – Constant Comparative method of analysing	Overall themes: I am not alone Friendships Helping others to understand Positive experience where they and not their parent, or their illness is the focus The value of challenge
2013							
USA							
Quality Score:							
75%							

Key for acronyms: IBQ- The Interaction Behavior Questionnaire; CDI – Children's Depression Inventory; RCMAS – The Revised Children's Manifest Anxiety Scale, CES-D – The Center for Epidemiological Studies Depression Scale; QoL – Quality of Life; EORTC QLQ-C30 – European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire; ILC – Inventory for Quality of Life in Children and Adolescents; SDQ – Strengths and Difficulties questionnaire; CASE – Cancer Self-Efficacy Scale; FRPQ – Family Peer-Relationship Scale; CBCL – Child Behaviour Checklist; SCL-90 – Symptom Checklist 90; BDI – Beck's Depression Inventory; FAD – Family Assessment Device; BYI – Beck's Youth Inventories

1.4.2 Child only interventions

Two of the reviewed studies involved group interventions for children only, and were evaluated using child and parent focus groups (Semple & McCaughan, 2013; Tucker *et al.*, 2013). A total of 19 children participated in the evaluations of these two studies. Tucker *et al.*'s (2013) intervention, 'On Belay', involved a focus on supporting children through building a sense of community and increasing feelings of efficacy around coping, by using an outdoor adventure programme. Unlike other programmes included in this review and otherwise reported in the literature, this was not focussed on talking and did not involve an educative component. The CLIMB® (Children's Lives Include Moments of Bravery) intervention used by Semple and McCaughan (2013) was more akin to the content and delivery of other interventions by providing six group sessions focussing on education, normalising feelings and increasing coping. This study scored highly on the quality appraisal procedures due to its detailed methodology and analysis procedures and the richness of the data generated.

Children in both of these studies commented on the normalising experience of being involved in these interventions and the benefits of peer support. By meeting other children they reported feeling less alone and isolated and found others that understood and empathised with their experiences and could offer them support. Children also described the groups as being a 'safe space' to detach from the difficulties of having a parent with cancer. In this environment they were distracted from their worries (Semple & McCaughan, 2013) and they, and not their parent or the illness, could be the focus. Parents too, described appreciating this as being

something good for their children, where otherwise there may be little opportunity for a good time, or that it may not feel acceptable to them to have fun given the circumstances (Tucker *et al.*, 2013).

In the CLIMB® programme there was an educative component and this was valued by children as being able to clarify any misconceptions, for example about their parent's illness (Semple & McCaughan, 2013). This was reported as resulting in decreasing worry and anxiety.

The positive impact of being able to cope as a result of the intervention was elicited by both evaluations. The 'On Belay' adventure group intervention's focus on challenge through activity meant that participants were able to gain a sense of mastery and accomplishment which could be used to reflect on their abilities to overcome challenges at home (Tucker *et al.*, 2013). Parents commented that as a result of attending the CLIMB® intervention, their children were using more adaptive coping strategies (Semple & McCaughan, 2013). This group of parents also described an improvement in mood and behaviour following the intervention. This did not emerge as a theme in the Tucker *et al.* (2013) evaluation. Both of these interventions incorporated a significant non-verbal emphasis (Semple & McCaughan, 2013, used art and play throughout their sessions). These techniques seemed to facilitate expression of emotion and facilitate alternative ways of improving coping strategies (Semple & McCaughan, 2013).

Although these interventions did not involve parents, parents spoke about the extent to which they benefitted from them in both evaluations. This involved relief that their child was being offered support, and the benefits to themselves of ad hoc support from other parents (Semple & McCaughan, 2013). Parents suggested an information session for them about how to facilitate their child's coping would be beneficial. This is a concept covered by other, family focussed interventions, discussed below.

By using qualitative research methodologies these evaluations are able to provide evidence of the perspectives and opinions of their participants, which may not be elicited through other evaluation methodologies. These two studies scored highly when assessing quality due to the employment of a rigorous methodology, and clear data analysis and reporting. However, quantitative analysis of outcomes would provide more specific indications of improvements or changes as a result of the intervention. For example, where parents in Semple and McCaughan's (2013) study comment on their perception of improvement in their child's mood and behaviour this is subjective and reliant on parental personal perspective only.

Focus groups were utilised for data collection in both studies. Tucker *et al.* (2013) specifically mention the employment of an investigator separate to the intervention to facilitate this focus group. This minimises the potential for bias in the information shared by participants. The involvement of a Family Support Worker from the cancer charity hosting the CLIMB® programme in the evaluation procedures of the Semple and McCaughan (2013) intervention may impact upon the data collected in this evaluation.

Children participating in the CLIMB® intervention (Semple & McCaughan, 2013) were children of parents already being supported by a cancer charity. Parents had initiated this professional support after identifying their own (and their families) need for it. In this way, although the CLIMB® intervention involved children alone, it is not possible to clearly discriminate the benefits of the specific CLIMB® intervention from benefits attained from general professional support (for parents as well as children) from the charity. Parents who do instigate help for themselves and their children may be more likely to report positive outcomes as a result of an intervention. Furthermore, they may have pre-existing resources which facilitate change that are not available for those families that do not initiate seeking help.

1.4.2.1 Summary of child only interventions

These two evaluations both report positive findings as a result of their respective interventions, elicited through qualitative evaluation of parent and child perspectives. In spite of differing overarching aims, philosophical backgrounds and group content and delivery these two intervention evaluations share several commonalities in outcomes.

1.4.3 Family-focussed interventions

The remaining eight studies included in this review focussed on evaluating interventions supporting the family as a whole, as opposed to exclusively the child. Of these, two (Bugge *et al.*, 2008; Bugge *et al.*, 2009) are two different analyses of

the same intervention. Both are included in this review as each analysis has a different focus and therefore offers a different contribution to the review.

The 'Enhancing Connections Program' (Lewis *et al.*, 2006) is the only intervention included in the review which aimed to support children by intervening through the mother only, without contact with the affected child. This intervention incorporated individual educational sessions with the mother with breast cancer and resources to use with her child. All of the other interventions involved contact by the facilitators with both children and at least one parent. The other, community based interventions reviewed here are a short term preventative counselling intervention for families (Thastum *et al.*, 2006); a specific culturally adapted (for an African American population) family intervention (Davey *et al.*, 2013); a trial incorporating two interventions to provide psycho-education and family support (Niemelä *et al.*, 2012) and a specific service to support children who have a parent with a diagnosis of terminal cancer (Kennedy *et al.*, 2008).

Two interventions (three studies; Bugge *et al.*, 2008; Bugge *et al.*, 2009; John *et al.*, 2013) were implemented within oncology inpatient settings. 'Getting Well Together' (John *et al.*, 2013) consisted of a rehabilitation focussed, manualised programme for mothers with breast cancer and their children. Its aim was to prevent adverse emotional and behavioural consequences in children by incorporating child-centred group interventions with regular oncological rehabilitation components (including psycho-educational health training and counselling sessions). Bugge *et al.* (2008; 2009) also utilised a manualised intervention, 'Family Talks in Cancer Care'. This

intervention aimed to support families' resilience through increasing the use of coping strategies in order to overcome challenges that may present when a parent has incurable cancer.

These studies vary with regard to the methodology, design and data analysis used and the outcomes measured. Five studies included a statistical analysis of outcomes based on self-report measures, two of which were also supplemented by data analysed qualitatively (Thastum *et al.*, 2006; Lewis *et al.*, 2006). Bugge *et al.* (2008; 2009) and Kennedy *et al.* (2008) used an exclusively qualitative methodology to explore children's and parents' perceptions of the interventions. Four of the five studies using quantitative methodologies refer to their evaluations as being pilot evaluations. The fifth, Thastum *et al.* (2006) can also be considered a preliminary evaluation. This study forms part of the multi-centre, multi-national (European) Children of Somatically Ill Parents (COSIP) research project. Thastum *et al.* (2006) utilised a sample of 24 families to preliminarily evaluate the efficacy of this intervention for families ahead of a proposed larger scale, naturalistic, semi-controlled trial (International Standard Randomised Trial Number Register, 2014). Overall these studies scored lower on the quality appraisal checklists than the evaluations using a qualitative methodology. This was largely due to them being pilot studies, and therefore not satisfying criteria with regards to sample sizes and methodological rigour (e.g. control groups and randomised allocation to groups) that may be employed in larger scale intervention evaluation studies.

1.4.3.1. Findings related to child well-being

Three studies reported significant improvements in an aspect specific to the child's emotional well-being following the intervention, as measured by pre and post intervention, self-report, standardised measures¹ (Thastum *et al.*, 2006; Lewis *et al.*, 2006; John *et al.*, 2013). These included decreases in levels of depression (Thastum *et al.*, 2006); improvements in cancer related worries, behaviour, anxiety and depression (Lewis *et al.*, 2006), and improvements in psychological health and emotional functioning (John *et al.*, 2013). Davey *et al.* (2013) report no statistically significant improvements on their measures specific to the child's psychopathology symptoms (anxiety and depression).

It is important to consider that these significant, positive changes reported for both children and parents (see below 1.4.3.2, *findings related to parental well-being*) are elicited from statistical comparisons across a wide variety of domains covered by the standardised questionnaires. For pilot tests particularly, exploratory data analysis of this nature can be useful to identify potential areas of change. However, multiplicity of testing increases the likelihood of reporting a false positive and it is therefore important not to over-emphasise subgroup findings (NICE, 2012). For example, Lewis *et al.*, (2006) use five child self-report measures to evaluate changes to the child's cancer related worries and behavioural and emotional functioning. Only one of these, 'cancer related worries' showed statistically significant change pre to post

¹ Please see table 1.2. for details of measures used for each evaluation

intervention. John *et al.* (2013) only, are explicit in their hypothesis testing of specific areas they predict to change as a result of their intervention. These hypotheses were derived from previous work by the authors, which found greater divergence of the group under study when compared to the general population on aspects of quality of life and emotional symptoms in children. These were, therefore, the primary hypotheses tested.

The use of quantitative methodologies and statistical analyses on samples of small sizes (see table 1.2 for sample sizes for each study) is a general criticism for these evaluations, including those detailed below also (*1.4.3.2 findings related to parental well-being*). Small sample sizes may reduce the selection of statistical analyses to non-parametric analyses and can result in studies being underpowered. This can act to reduce the validity of these evaluations. Lewis *et al.* (2006) acknowledge that results from their study should be viewed as suggestive.

All of the evaluations report on the reliability and validity of the established, standardised measures they selected. This is an identified strength for the quantitative methodology evaluations, as elicited by the quality appraisal procedures. However, general criticisms about the use of self-report measures to establish the presence of change may be exacerbated by the use of proxy questionnaires where a parent reports on their child's functioning. John *et al.* (2013) used proxy questionnaires exclusively in their analysis and Lewis *et al.* (2006) used both questionnaires for children and parents to measure the child's anxiety and depression. In this evaluation (Lewis *et al.*, 2006), although significant improvement

in the child's anxiety and depression were reported following the 'Enhancing Connections Program', this was taken from the parental measure. No significant improvement was established from children's direct reporting. This indicates the potential for discrepancy in outcomes, dependent on the perspective evaluated and the need to consider the relative value of children and parental reports on change when evaluating interventions.

Thastum *et al.* (2006) included a qualitative analysis on children's perspectives of what they gained from the intervention. Specific to their own well-being, children reported finding the counselling beneficial in normalising and validating their emotions. Bugge *et al.* (2008) and Kennedy *et al.* (2008) used a qualitative methodology to evaluate their interventions. Bugge *et al.* (2008) found that children reported that the intervention supported them to talk to their parents, increased their factual knowledge, and led to a greater awareness of how to cope with their emotions. An important criticism of the findings of the Bugge *et al.* (2008) study emerged during quality appraisal procedures. The themes derived are concerned more with children's experiences of the intervention, whereas the aims of the evaluation were to explore the impact of the intervention on the children. Furthermore, major findings reported in the abstract are not clearly identifiable from the main text results section. These both impact upon the 'trustworthiness' of the evaluation and the extent to which the validity of the study can be assumed.

1.4.3.2 Findings related to parental well-being

As well as measuring outcomes on children's well-being, the above three studies also report improvements in parental outcomes following the interventions (Lewis *et al.*, 2006; John *et al.*, 2013; Thastum *et al.*, 2006). Thastum *et al.* (2006) and Lewis *et al.* (2006) report improvements in depression; Lewis *et al.* (2006) additional improvements in anxiety and self-efficacy, and John *et al.* (2013) report an increase in the mother's emotional functioning. As before, with children's depression and anxiety levels, no significant outcomes for parents were found in the Davey *et al.* (2013) study, who investigated the impact of their intervention on parental depression.

The aims of the preventative counselling intervention evaluated by Thastum *et al.* (2006) would not anticipate a reduction of parental symptoms of depression, as acknowledged by the authors themselves. This unexpected finding might indicate the value of these interventions to parents by reducing their concerns about parenting, and increasing their peace of mind, through improving the child's well-being. There is, however, an important criticism of the Thastum *et al.* (2006) research design identified through quality appraisal procedures, which is a potential source of bias in the study. A control group of patients who did not choose to participate in the counselling intervention was found to have statistically significant lower levels of depression at baseline than those in the intervention group. Hierarchical regression analysis found that baseline depression explained a significant 57% of the variance (β -68, $p < .0005$) meaning that elevated levels of depression at baseline could explain the significant changes on standardised measure scores.

Niemelä *et al.* (2012) only report on changes to parents' psychiatric profiles in their publication of data from a pilot trial of structured child-centred interventions (outcomes related to children are not available). This pilot trial precedes a proposed larger, randomised controlled trial for families with a parent with cancer; 'The Struggle for Life: A Preventative Intervention'. Two separate interventions are used within this trial; 'Let's Talk about the Children' and the 'Family Talk Intervention'. This pilot study contained completed data for 10 families at 4 month follow up after intervention completion. A significant decrease in the level of the parents' psychopathology was found 4 months following the intervention for both the ill parent and their spouse. However, attrition rates for this pilot evaluation are high, with only 10 of the 19 families completing baseline measures going on to complete the 4 month follow up measures. As an indication of potential confounding variables for those who completed versus those who did not are not provided, it may be that this high rate of attrition is a potential source of bias, affecting the validity of the study. Details of whether families participated in either or both of the included interventions are not provided, meaning elucidation of the specific intervention components that may be contributable to observed outcomes is not possible.

Qualitative analyses relating to parental well-being found parents gained feelings of confirmation of their parenting abilities and choices (Bugge, *et al.*, 2009; Thastum *et al.*, 2006); improvements with their skills in dealing with their own thoughts and emotions (Bugge *et al.*, 2009; Lewis *et al.*, 2006) and support to listen to and

understand their children (Bugge *et al*, 2009.; Lewis *et al.*, 2006). These outcomes relate closely to changes noted in overall, general family functioning.

1.4.3.3. Findings related to general family functioning

Overall family functioning, communication and relationship quality were common evaluative components of these family-focussed studies. Where these were measured by self-report questionnaires, outcomes emphasised improvements in communication (Davey *et al.*, 2013; Thastum *et al.*, 2006) and affective responsiveness and general family functioning (Thastum *et al.*, 2006). Qualitative analyses also highlighted the positive outcomes of the interventions on family functioning. These included an improvement in understanding of emotions, and of each other (Lewis *et al.*, 2006; Thastum *et al.*, 2006), increased intimacy and cohesion, and increased normalisation of feelings within the family (Thastum *et al.*, 2006). Participants in Kennedy *et al.* (2008) reported the intervention as being there to 'hold them steady' and stabilise them as they negotiate their experience of having a parent with terminal cancer. Although this study focusses on the impact of the intervention upon families, specific outcomes with regards to families are not the emphasis of the evaluation.

An apparent contradiction exists in the Lewis *et al.* (2006) evaluation with regard to outcomes for mother-child relationships. When measured on a standardised measure, no significant improvements were found. However, positive reports regarding improvements in this area were described in their qualitative analysis. This indicates the value of a mixed methodology where qualitative analysis can enhance

findings from quantitative analysis of outcome measures and generate themes and findings not shown by pre-existing measures.

The findings reported by the Davey *et al.* (2013) study highlight the importance of the valid selection of outcome measures, which reflect the aims and anticipated outcomes of the intervention. Although a primary aim of the intervention was to improve parent-child attachment, they did not select a specific attachment measure and were not, therefore able to test this specific intervention aim.

1.4.3.4. Summary of family-focussed interventions

Family-focussed interventions have been implemented in both community and inpatient services and evaluated with quantitative and qualitative research methodologies. Findings indicate positive outcomes for children and parent well-being including some improvements in levels of anxiety and depression in both children and parents, as well as overall family functioning. These findings are mixed, however. Methodological limitations of these evaluations means that the validity of the studies must be considered when interpreting these findings.

1.5. Discussion

1.5.1. Summary and discussion of findings

The evaluations included in this review may indicate positive outcomes for children and their families as a result of participation in interventions designed to support children who have a parent with cancer. Limitations in evaluation methodology

however mean that these findings should be interpreted with caution. Findings have been derived from evaluations using quantitative and qualitative research methodologies. Standardised self-report measures have shown improvements in children's emotional well-being; including levels of depression, anxiety, behaviour and general psychological health. Improvements have been reported too, for parents, regarding mood, anxiety, and overall emotional functioning. Benefits to overall family functioning are also indicated. These include improved communication, better understanding of one another's' emotions and responses and increased intimacy and cohesion. Qualitative studies have permitted a greater elicitation of details regarding the benefits of participation in these interventions and, as perceived by the families.

Two of the interventions included in this review were designed to support children only, within peer groups and without their parents. The remaining eight were family focussed in their aims and delivery. This imbalance may be indicative of a shift in the current understanding of the best way to intervene to support this group of children. There was a greater inclusion of child only interventions in Niemalä *et al.*'s (2010) review, the most recent of which were from 1996. Schmitt *et al.* (2007), advocate the benefits of family-centred psychosocial support in their review of the literature on mental health and coping when a parent is somatically ill.

It is not the aim of this review to establish comparative efficacy of either intervention design. However, consideration can be given to the outcomes for children and families in relation to the role of parental involvement within the intervention.

Outcomes from the family focussed studies highlight improvements in family communication, affective responsiveness and intimacy, as well as improvements in parental mental health. The value of open, responsive, familial communication in promoting adjustment and psychological well-being in children, is established in the literature (Gentzler, Contreas-Grau, Kerns & Weimer, 2005). The role that parental mental health can have upon on a child's mental health is, also (Beardslee, Versage & Gladstone, 1998; Manning & Gregoire, 2008).

This relationship between child and parental well-being is likely to be cyclical. Relief regarding their children receiving the support they need may act to improve the parent's emotional well-being. This is indicated through the declared benefits of this nature spoken of by parents who were not involved in the intervention (Tucker *et al.*, 2013), as well as the objectively measured improvement in parental depression and/or anxiety (Niemelä *et al.*, 2012; Thastum *et al.*, 2006). Rauch (2007) concludes that 'parents are only as happy as their most unhappy child' when reflecting on her experience of working with parents who have cancer. Interventions may have an emotionally containing function (Bion, 1962) for parents as well as children, both directly benefitting the parents and enabling them to further act to support their children. For some children, however, the focus on them and not their parents or their parent's illness was beneficial (Semple & McCaughan, 2013), and this was a criticism voiced by children receiving an intervention where they felt they weren't the emphasis (Thastum *et al.*, 2006).

Children commented on the value of normalisation and validation as a consequence of participating in the interventions. Psycho-education was a further valued component and the majority of interventions included in this review included a psycho-educational component. This was reported to be useful by the children as it permits clarification of misconceptions, which can reduce children's feelings of anxiety. Previous research has indicated that children will develop their own explanations, sometimes erroneous ones, when they do not have the facts. This may lead to feelings of guilt if they attribute their parent's illness to their own behaviour (Armsden & Lewis, 1993).

Variations and contradictions exist in the outcomes reported across these evaluations. This can be attributed to variances in intervention aims, or, indeed, potential intervention efficacy, with some producing more positive outcomes than others. They may also be attributable, in part, to variances in, and limitations of, evaluation methodology.

1.5.2. Consideration of methodological limitations

1.5.2.1. Study designs

The study design employed in an evaluation can influence greatly the validity of the findings. All of the evaluations included in this review which used a quantitative methodology were preliminary or pilot evaluations. As well as the limitations of the small samples utilised within these studies, the lack of a randomised control group, or in some instances any control group, was another major contributing factor to the low quality appraisal ratings assigned to these studies.

Two of the evaluations utilised a control group design (Davey *et al.*, 2013; Thastum *et al.*, 2006). These comprised those who had not opted in to the counselling intervention (Thastum *et al.*, 2006); and a group receiving a standard psycho-education intervention (Davey *et al.*, 2013). John *et al.* (2013) used a within subject control by taking pre-intervention measures 6 weeks prior to intervention and then a few days after commencement. In this way they were able to control for waiting period changes. This was especially useful in this study where the inpatient stay may have acted as a form of respite for families, and therefore result in improvements without the implementation of the intervention. In the design used by Thastum *et al.* (2013) those that opted to participate in the intervention showed greater levels of depression than the control group. This may have implications upon the generalisability of their findings regarding decreased levels of depression in mothers. There was no difference at baseline between the intervention and control group in Davey *et al.*'s (2013) study, although they only report demographic comparisons and do not report comparisons between groups on outcome measures.

Randomised Controlled Trials (RCTs) are considered to be the most rigorous way to determine the cause-effect relationship upon outcome following an intervention. None of the intervention studies included in this review were RCTs, although intention to conduct larger scale controlled studies (randomised in one instance) is discussed. Clinical and ethical implications of RCTs may make these more difficult to implement (for example, John *et al.*, 2013, report bureaucratic demands of the German health care system restricting the inclusion of a randomised control group

in their evaluation). Samples in these studies, with the exception of Davey *et al.* (2013), self-selected to treatment groups and were often opportunistic. Although some procedures are implemented to ascertain potential bias in the samples, this may still impact upon the reported effectiveness of the interventions.

Self-report measures, where utilised, were validated, standardised and reliable. However, reliance on self-report measures can affect the validity of an evaluation, as the objectivity is questionable. Achenbach *et al.* (1987) report a correlation of just 0.24 between children's self-report and parents' reports of their children's emotional and behavioural problems. This disparity may be compounded further by additional constraints placed on families by cancer (Osborn, 2007). This raises an important question about the reliability of findings that rely solely on a single perspective, or make claims about improvements based upon one perspective.

Variations in when post-intervention measures are taken exist within these evaluations. Niemelä *et al.* (2012) specify that their follow-up was 4 months following the completion of the intervention and John *et al.* (2013) gathered post intervention measures within 2-3 weeks after arrival at the intervention. For other studies the time frame is not clear. Consideration of when post-measures are taken is critical in establishing potential longer-term benefits. Niemelä *et al.* (2012) discuss their intention to take 18 month follow up data, although this is not currently accessible.

Where qualitative methodologies are employed these can complement quantitative data to enhance the richness of the evaluation. Qualitative methodologies may also

elicit information pertinent to outcomes for parents and families which may not be covered by standardised measures that are often designed to measure psychopathology. Exclusively qualitative studies have varied in the quality of the design employed, analysis conducted and reporting of findings. It may be arguable also, that they are restricted in their absence of an objective measure of perceived changes as a result of the interventions.

1.5.2.2. Cultural considerations

These intervention studies involved a predominantly white, western demographic, with only one study commenting on cultural influences or considerations. Davey *et al.* (2013) evaluated an intervention specifically designed to meet the African-American demographic in America. Although they clearly provide a rationale for the benefits of this cultural specificity, the study design does not allow for the specific benefits (or not) of this aspect of the intervention to be elucidated. They report difficulties with recruiting to the study. As they propose, more work may be required to successfully engage this group with appropriate interventions, where making them culturally specific is an important measure in enhancing engagement. This resistance to participate may also explain the under-representation of this demographic in the other intervention studies.

1.5.3. Limitations of the review

This literature review was conducted in a systematic way in order to critically analyse evaluations of interventions that include outcomes for children and families.

However, there exist some limitations which may affect the overall validity of the review.

Any review that excludes studies based upon the language they are written in results in some bias. However, the inclusion of only English language studies in this review may be particularly pertinent when considering the dominance of research in this field being European.

Studies were restricted for inclusion to those published since 2004. In doing so, this review provides an up-to-date critical analysis of interventions being used, based upon current research and ideology. However, it may be that evaluations pre-dating 2004 could add further contributions to the analysis and enrich the review further. Examination of earlier studies (for example, those included in Niemelä *et al.*, 2010) does suggest, however, that these involved weaker evaluations, if, indeed evaluation specific to outcomes for the children and families were conducted at all.

The decision to not exclude interventions focussing specifically on terminal cancer was a considered one. This difference in prognosis is likely to result in a different pattern of difficulties and support needs for the families affected. However, wide variances within families affected by cancer are reported regardless, and, as some interventions do not specify inclusion or exclusion based upon cancer stage, their inclusion seemed appropriate, and their contribution to the review important.

1.5.4. Clinical implications

This review indicates the value of supporting children and their families when a parent has a diagnosis of cancer, to improve the emotional well-being of children and their parents. In spite of this, only two of the studies included in this evaluation were UK based, one conducted in Northern Ireland and one in Scotland, the latter funded by Macmillan Cancer Support. UK government and health guidance is notable for its absence of specific consideration or recommendations for children who have a parent with cancer. This is in spite of Department of Health (DOH, 2011) promotion of mental health and prevention of mental ill-health, which includes an emphasis upon the role of early intervention with children. These factors suggest a disparity in addressing the needs of these children in the UK.

What constitutes an intervention, and whether these are provided for children with or without inclusion of their families, varies across the interventions included in this review. However, the following are clinical recommendations drawn from the findings of this systematic review, for professionals who work with children who have a parent with cancer, or who are developing an intervention designed for this purpose:

- An emphasis upon the validation and normalisation of the child's feelings, thoughts and responses.
- The inclusion of a psycho-education element about cancer, in order to reduce any anxiety that the child might experience arising from misunderstandings.

- Counselling, or an equivalent method of intervention designed to enhance open communication and stabilisation of family relationships.
- Provision of an opportunity for the child to have time with the clinician alone, to have their voice heard.
- Parents benefit from intervention also. If this is not offered as part of a family intervention, specific thought with regards to where parents may seek equivalent support from should be given.

1.5.5. Future directions

Larger scale naturalistic and randomised controlled trials of interventions are already planned. These will provide further evidence, using stronger evaluative methodology, as to the utility of the interventions they evaluate. Ongoing evaluation specific to the outcomes for children and families, as well as evaluations of implementation will aid practitioners and commissioners in identifying the value of such interventions and how best to support the children for whom they are designed.

1.6. Conclusion

Recent evaluations of interventions designed to support children who have a parent with cancer indicate positive outcomes for children and parents. These findings must be interpreted within the context of the methodological limitations of this body of research. Well-controlled, large scale evaluations are required to enhance the reliability of the findings. The implications for UK service provision and clinicians working with children who have a parent with cancer have been considered.

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Chapter 2: Empirical Paper

The lived experience of malignant melanoma: diagnosis, treatment and beyond

Prepared for submission to Journal of Psychosocial Oncology (please refer to Appendix A for instructions for authors for submission)

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2.1. Abstract

Aims: A diagnosis of malignant melanoma can result in a range of emotional reactions and psychological distress. In spite of this, little research has been conducted into the experiences of malignant melanoma survivors, from their perspectives. This study aimed to explore in detail the experiences of people who have had melanoma and the sense that they have made of their experience.

Method: Six participants were recruited to this study. Semi-structured interviews were conducted and analysed according to Interpretative Phenomenological Analysis (IPA).

Results: Three superordinate themes emerged from the data; 'It is serious, isn't it?', 'Finding an equilibrium' and 'A chapter closed?'. Participants' experiences were characterised by a tension between malignant melanoma being a serious life event, or not. This was influenced by their own and others' perceptions. Their ways of restoring balance for themselves and coping with their situation and the value of support emerged as a significant part of their experience. Finally, participants considered the ongoing impact of having had melanoma, and the longer-lasting effects of this experience.

The clinical implications of the findings and future directions for research are discussed.

Keywords: *malignant melanoma, lived experience, Interpretative Phenomenological Analysis, IPA*

2. 2. Introduction

2.2.1 Malignant melanoma in context

Skin cancer accounts for one in three of all cancer diagnoses, and its incidence continues to rise (World Health Organisation, 2014). Non-melanoma skin cancers account for approximately 95% of skin cancers and the most common forms of these are basal cell carcinoma and squamous cell carcinoma (Macmillan, 2011). Malignant melanoma, although less common, is responsible for 80% of skin cancer deaths (Cancer Research UK, CRUK, 2014). Unlike non-melanoma skin cancers, which exist in the epidermis, malignant melanoma can spread to surrounding tissue, and if not treated quickly enough, other organs (CRUK, 2014). Melanoma can present both as changes to an existing mole, or in previously normal skin. Although the causes of malignant melanoma are considered multifactorial, ultra-violet radiation exposure is widely considered a primary factor in its aetiology (Narayana, Saladi & Fox., 2010). Treatment consists primarily of excision of the mole (or affected area) and of the surrounding tissue. In the instances of melanoma that has spread, radiotherapy or chemotherapy may be required (Macmillan, 2011).

2.2.2 Epidemiology of malignant melanoma

Incident rates of malignant melanoma have increased by 55% from 1999-2001 to 2008-2010, with 13,348 new cases in the UK in 2011. Since the 1970s rates are seven times higher in men and four times higher in women. This means malignant melanoma has increased at a higher rate than any of the current ten most common cancers (CRUK, 2014).

Skin cancer, when compared to other cancers, has risen dramatically in younger populations, particularly young women. The average age of diagnosis is considerably younger than other cancers (Guy & Ekwueme, 2011). More than two 15-34 year olds are diagnosed with malignant melanoma every day in the UK (British Skin Foundation, 2012). Morris, Cox, and Bosanquet (2009) estimate the total cost of skin cancer in England alone to be £240 million.

Prognosis for skin cancer and malignant melanoma is often good. Cancer Research UK (2014) cite observed 5 year survival rates for Stage I melanoma to be between 88-95% (see Appendix C for details on stages of malignant melanoma). In spite of this prognosis, there is evidence of emotional and psychological impact at initial diagnosis and beyond (Al-Shakhil, Harcourt & Kenealy, 2006; Brandberg, Mansson-Brahme, Ringborg & Sjoden, 1995; Wheeler, 2006).

2.2.3 Emotional, psychological, behavioural and cognitive responses to melanoma

In a systematic review of the literature Kasparian, McLoone and Butlow (2009) report that approximately 30% of all patients with melanoma describe levels of psychological distress and anxiety indicative of the need for psychological intervention. For some, this distress may continue years following diagnosis and treatment. The most commonly reported psychological difficulties associated with melanoma are anxiety and depression (Zabora *et al.*, 2001). Furthermore, Zabora *et al.* (2001) compared clinically significant levels of distress across different cancer sites. They found patients with melanoma experience levels of distress similar to

breast and colon cancer and greater than prostate and gynaecological cancer. This is in spite of their relatively positive prognoses. Perhaps supporting the idea that prognosis itself is not indicative of psychological distress, Brandberg *et al.* (1995) noted no difference in psychological problems between two groups of malignant melanoma patients with different prognoses (tumours greater or less than 0.8 mm in depth). These studies all used pre-existing measures to elicit their findings and were analysed using quantitative methods.

The person's interpretation of, and subjective beliefs about, the melanoma may be more pertinent in considering the psychological impact upon them (Folkman and Guer, 2000; Hamama-Raz, Solomon, Schachter, & Azizi 2007). Furthermore, the nature and quality of psychological responses may vary as a function of where in the melanoma trajectory, from diagnosis to follow up, a patient is (Kasparian, 2013; Kasparian 2013a).

Few research studies report no detriments to well-being following diagnosis with malignant melanoma. Cassileth, Lusk and Tenaglia (1982) found patients with melanoma to be equal to the general public in terms of emotional well-being. When considering overall quality of life Eakin *et al.*, (2006) found people who had had melanoma fared better compared to other cancer sites at a long-term follow up. The measure of quality of life used within this study included just one question; "How do you feel about your life as a whole, taking into account what has happened in the last year and what you expect to happen in the future" (Andrews and Withey, 1976) with Lickert scale response options. Using a more thorough measure, Schlesinger-Raab *et*

al. (2010) report quality of life two years later to be comparable to a general population. This seems to support the findings of Cassileth *et al.* (1983).

An individual's coping styles and psychological resilience is likely to be related to the psychological distress they exhibit. Coping has been described as the attitudes, actions and beliefs with an adaptive purpose employed by a person when faced with a threatening situation (Kneier, 2003). Coping acts to protect the emotional state of the individual and to allow for psychological adjustment. Kneier posits several useful strategies for coping with the diagnosis and treatment of melanoma including maintaining hope, facing reality, expression of emotions, seeking support from others, and not being avoidant. A review by Kasparian *et al.* (2009) finds that active and problem focussed coping strategies are indicative of better adjustment to melanoma. Sollner *et al.* (1999) emphasise the importance of good social support alongside active coping strategies in predicting good adjustment. The vast majority of research exploring responses to melanoma is dominated by research using quantitative methodologies.

2.2.4. Qualitative research and malignant melanoma

In spite of the evidence of the potential impact of melanoma, and the emotional and psychological distress caused as a result of it, there remains very little research into the area, particularly using qualitative methodologies (Oliveria *et al.*, 2007; Wheeler 2006; Winterbottom & Harcourt, 2004). Qualitative research is valuable in the field of health psychology because it can obtain a richer account of how a person is thinking about and dealing with health related questions, without the confines of

pre-determined categories, such as those that are implemented in quantitative research designs (Pope & Mays, 1995; Smith, 1996). In this way, it is more sensitive to understanding why people behave as they do and exploring how people make sense of, and find meaning in, their illnesses (Smith, 1996).

Barker *et al.* (2011) conducted a systematic review of qualitative work looking at the needs and experiences of patients through the skin cancer journey. This review included only two studies, indicating the clear lack of research in this area.

One of the studies in the Barker *et al.* (2011) review was a qualitative analysis of patient experiences of diagnosis and treatment of skin cancer (Winterbottom & Harcourt, 2004). Using participants in the UK, Winterbottom and Harcourt interviewed sixteen patients with different skin cancer diagnoses (malignant melanoma, basal cell carcinoma and squamous cell carcinoma). Thematic content analysis revealed that malignant melanoma patients differed from other skin cancer patients on the range of coping strategies used, and the diagnosis seemed to have had a more profound effect on their lives.

Qualitative research specifically considering malignant melanoma is limited. Two studies published since the Barker *et al.* (2011) review have begun to address this with qualitative research looking at specific, pre-defined experiences of melanoma patients (McLoone *et al.*, 2012; Oliveria *et al.*, 2013). Oliveria *et al.* (2013) conducted focus groups with 48 participants to examine their experiences regarding sun protection, surveillance practices and psychosocial concerns. Through a process of

thematic analysis they found that skin self-examination and anxiety regarding sun exposure were major concerns to participants. McLoone *et al.* (2012) conducted telephone interviews with patients at high-risk of melanoma reoccurrence. Critical to this group were worries about developing new disease, sometimes for many years following treatment completion.

2.2.5. Rationale and aims of current research

Emotional and psychological difficulties have been established to be a reality for malignant melanoma survivors (Kasparian *et al.*, 2009; Zabora *et al.*, 2011). The vast majority of research in this area has been quantitative, using questionnaires and pre-existing standardised measures. In this way it has been guided by researchers and the tools which they use rather than presenting an account of a patient's perspective (Winterbottom & Harcourt, 2004). Qualitative research into skin cancer and coping is limited with a paucity looking at malignant melanoma. Recent qualitative research addressing this gap (McLoone *et al.* 2012; Oliveria *et al.* 2013) has done so with regards to specific areas or sub-populations and analysed this research using thematic or content analysis methodologies. The methodologies employed by these studies may act to limit the depth of experiences elicited in the data.

This research seeks to further address the gap in exploratory qualitative research looking in depth at the lived experiences of patients with malignant melanoma. To date, research has not been conducted that has utilised a methodology which can afford such an immersion in the experiences as perceived by participants. A highly detailed, idiographic approach is anticipated to offer further insight in to the specific

experiences of this group. The research aims to provide an exploratory overview of experiences at diagnosis, treatment and beyond, with an emphasis on the lived experience of the journey. It is anticipated that this research will add depth to knowledge about patients' experiences, the sense they have made of them, and their needs and how this might influence provision of clinical input and support.

2.3. Method

2.3.1 Research design

A qualitative research design was selected to meet the aims of this research due to its exploratory nature (Smith, 2008). Interpretative Phenomenological Analysis (IPA) was selected as the methodology due to its emphasis on an idiographic, detailed exploration of individual participant experiences and the meaning that particular experiences and events hold for them (Smith & Osborn, 2008). IPA is phenomenological in that it seeks to understand the participant account from their perspective rather than from an objective reality (Smith & Osborn, 2008). This methodology recognises the role of the researcher within this process when analysing and making sense of the phenomenological perspective of each participant. IPA is now well-established as a methodology for those seeking to understand the experiences of those with a wide variety of health conditions (Smith, 2008a).

2.3.2. Participants

Patients who had successfully completed treatment by excision of Stage I or II melanoma were invited to participate in the research. Melanoma at stages I and II is most prevalent and share similar treatment pathways and prognosis. Further inclusion and exclusion criteria for participation are detailed in table 2.1 below.

Table 2.1. Participant inclusion and exclusion criteria

Inclusion criteria	i)Diagnosis of and treatment completion for malignant melanoma ii) Melanoma at stage I or II iii) Within 18 months post-surgery iv) At least 18 years of age
Exclusion criteria	i) Non-English speaking

Six participants were recruited, 1 male and 5 females. Six was considered an appropriate number for this IPA study so that a commitment to a detailed interpretative account of each individual cases was upheld, whilst also allowing for an examination of similarity and difference, convergence and divergence (Smith, Flowers and Larkin, 2009). All participants described themselves as White British and aged from 36-45 to 75+, indicating good homogeneity of the sample. Table 2.2., over, provides further participant details. All names are pseudonyms.

Table 2.2. Participant details

Participant	Age	Melanoma site	Time since treatment completion
Mary	66-75	Foot	4 months
Tony	36-45	Back	9 months
Dawn	36-45	Forearm	4 months
Lilian	>75	Leg	12 months
Anne	56-65	Leg	15 months
Claire	36-45	Foot	18 months

2.3.3. Procedure

2.3.3.1. Ethical procedures

The research was designed in accordance with guidance by the British Psychological Society (BPS, 2010). Ethical approval was gained from Coventry University (Appendix D) and a NHS Research Ethics Committee (see Appendix E). The study was registered with both NHS Research and Development (R & D) departments (Appendix F).

2.3.3.2. Materials

A semi-structured interview schedule was utilised (see Appendix G), as recommended for IPA methodology (Smith, Flowers & Larkin, 2009). This was developed to be intentionally broad utilising a flexible, non-leading, open ended framework for questioning to allow the participant to lead the dialogue with the information and experiences most pertinent to them. Questions were designed with consideration of the research aims, existing information in the literature and liaison with skin cancer Clinical Nurse Specialists and the supervision team.

2.3.3.3. Recruitment

Two National Health Service (NHS) dermatology departments were involved in recruitment of participants. Potential participants attending follow-up appointments with skin cancer Clinical Nurse Specialists (CNS) and who met the inclusion criteria, were provided with a participant information pack. These included a participant information sheet (Appendix H) and response sheet (Appendix I) to be returned to the researcher to express interest in participation. Ten response sheets were returned. After telephone contact with potential participants, eight met the inclusion criteria, a further two later decided they did not wish to participate in the study and six participated.

2.3.3.4. Interview procedure

Participants were provided with the participant information sheet to review once more and given an opportunity to ask the researcher any questions. Written consent was then provided by the participant (see Appendix J for a copy of the consent form). Basic demographic information was collected to situate the sample. A semi-structured interview was conducted with participants at their preferred location, which for all participants was at their home. Interviews lasted between 39 and 90 minutes (mean, 55 minutes) and were audio-recorded. Following the interview participants were given the opportunity to ask the researcher any further questions and were provided with de-briefing information (Appendix K).

2.3.4 Analysis

Following each interview, audio-recordings were transcribed verbatim. Identifying information was removed and participants provided with a pseudonym. This data was then analysed according to the IPA methodology detailed by Smith, Flowers and Larkin (2009; see Appendix L for analysis steps). An excerpt of a transcript with initial noting is included in Appendix M, as well as an example of themes developed and clustered for one participant (Appendix N). This was repeated for all participants before patterns across cases were considered and overall themes elicited. These were then clustered to provide sub-ordinate themes within super-ordinate themes.

2.3.4.1 Validity of the study

Yardley (2000) describes criteria for assessing quality in qualitative research. These criteria have been used throughout this research to enhance the validity of the study. Transcripts, initial coding, emerging themes and final themes were discussed with the principal researcher's supervisors who are experienced with IPA methodology. Coding of a single transcript was also conducted by a peer and similarities and differences between these and the researcher's codes and emerging themes were discussed and reflected upon.

2.3.4.2 The researcher's position

The researcher was a Trainee Clinical Psychologist who had no prior involvement with the NHS departments involved in the recruitment to the study. The hermeneutic underpinning of IPA methodology requires the researcher to be committed to understanding her own pre-conceptions and how these may impact upon the interpretative engagement with the data. A bracketing process incorporating an

interview and ongoing reflective practice was employed. This facilitated the researcher to understand her own assumptions and beliefs. Prior to the research starting the researcher anticipated the role of tanning and sun-behaviour as a potentially important part of the experience for this population, perhaps constructed for her from the wide-exposure afforded to this risk in the media through her lifespan.

2.4. Results

Following analysis of the data, three superordinate themes emerged; 'It is serious, isn't it?', 'Finding an equilibrium' and 'A chapter closed?'. Each one consists of three subthemes. These are displayed in table 2.4. and discussed narratively with consideration to the convergence and divergence within themes.

Table. 2.3. Superordinate and subordinate themes

Superordinate theme	Subordinate themes
Theme 1. It is serious. Isn't it?	<ul style="list-style-type: none"> a) "Devastation" at diagnosis b) Melanoma as a threat to life c) A desire to be taken seriously
Theme 2. Finding an equilibrium	<ul style="list-style-type: none"> a) Dealing with it b) Perspectives on support c) In the context of "what life dishes out"
Theme 3. A chapter closed?	<ul style="list-style-type: none"> a) It's in the past b) Expert mole checker c) Incorporating the experience in to a sense of self

2.4.1. Theme 1. It is serious. Isn't it?

All participants communicated their thoughts and reflections regarding the tension between whether having a diagnosis of melanoma, the treatment, and its sequelae was a serious life event, or not. This was presented within the context of their own feelings and experiences as well as the reactions and responses of others. This theme is discussed below under the subthemes "'Devastation" at the diagnosis', 'Melanoma as a threat to life' and 'A desire to be taken seriously'.

2.4.1.1. Theme 1a. "Devastation" at the diagnosis

All participants experienced shock following their diagnoses of melanoma. For three participants in particular this was represented as feelings of loss, fear and disbelief with a coinciding strength of emotional reactions at this time. Anne, for example, considers the shock at diagnosis to be the worst part of her experience and talks here about her reactionary devastation at receiving her diagnosis, particularly with relation to her anticipated impact upon her lifestyle:

Well, oh god, I was absolutely devastated, because of what had gone on in my life anyway, and I thought, god, that's another thing, because I do go on a lot of holidays and that is my life, I've got nothing else..... I'm finished.

(Anne, 18-22)

The strength of the impact of this diagnosis upon Anne is made clear with her consideration that not just her lifestyle, but indeed the whole of her, is "finished" as a result of it.

This shock appeared to be influenced for some by their perception of the mole that had resulted in the melanoma. Five participants shared prior perceptions of their mole as innocuous and insignificant and therefore their surprise that it could result in such an outcome. In this way the perception prior to diagnosis that it would not be anything serious was soon shattered:

When they actually told me, I thought “my god” you know, you wouldn’t have thought that such a little mole could do so much damage. And I was really shocked.

(Claire, 89-91)

For Anne, Dawn and Tony particularly the use of the word *cancer* and the connotations of having a *cancer* diagnosis were at the core of their shock. Not only was this, for these participants, an unexpected outcome but it also evoked feelings of fear. Dawn describes within the first few lines of her account how the consultant’s first words to her in her first meeting with him were “that’s cancer”. Although later on in her account it emerges the process actually involved awaiting the return of the biopsy results, Dawn’s placing of this information earlier in the process, and with such emphasis, highlights the poignancy of this element of the experience for her:

The consultant, first thing he said “that’s cancer”....and that was like the “bang” moment....So it was from nothing to that sort of big, sort of, “oh my life”, because nobody in my family had had it so expectations, absolutely nothing.

(Dawn, 7-12)

Furthermore the introduction to a Macmillan cancer nurse at this point contributed to these participants' fears surrounding the diagnosis, as a result of their understanding of the connotations of this. For all participants, the diagnosis evoked in them thoughts about death. These thoughts appeared to be both derived from fear and anxiety, and the diagnosis as being a trigger for thoughts of inevitable mortality:

...think "oh my god, I'm going to bloody die now".

(Tony, 178-179)

....and I said to him well it looks as if I'm on the cards, I could go first.

(Lilian, 139-140)

For some participants these appeared to be fleeting, reactionary thoughts, whereas for others thoughts about mortality were more extended (see theme 1b, below).

2.4.1.2. Theme 1 b. Melanoma as a threat to life

All participants spoke, at some point in their experience, about thoughts about death and/or having considered their own mortality. Some participants had explicit thoughts about death as illustrated above in theme 1a. For others, behaviour at that time may have indicated to them, upon reflection that this had concerned them:

I can remember before going in for this second excision I ought to clean out these cupboards and drawers as my husband wouldn't have a clue and would he want to do it and all the rest of it (*laugh*) and I did take a lot of stuff down to the charity shop then. I don't

know if I was frightened of my own mortality then.

(Mary, 275-278)

For Tony and Claire, however, this was a pervasive concern and a re-occurring theme of their narrative:

....because I'm only 42, I did say to her [Cancer Nurse Specialist]
that I think it will get me eventually.

(Tony, 526-527)

For these participants, months after treatment they were still concerned with thoughts about a threat to their own life and, for Claire, who was acutely aware of the heritability of the condition, her children as well.

References were also made to multiple incidences of other people who have died because of melanoma or who have advanced metastatic cancer as a result. In this way it could be said they are using other peoples' stories as a way to communicate and make sense of their concerns for themselves:

I didn't realise it could actually kill you if left. I found out
after this was done and she [mother] was like, my granddad
left his.

(Claire 158-163)

There are quite a few terminal on there [online support group],
that are Stage 4 and they've got brain mets, and you know,
quite poorly.

(Tony, 459-462)

This also indicates an increased vigilance and awareness to the potential seriousness of the condition and the potential for death, demonstrating their acute and ongoing awareness of the threat to life melanoma can pose.

2.4.1.3. Theme 1 c. A desire to be taken seriously

Participants differed in their needs to have their condition and experiences acknowledged by others. For Tony and Claire, others' perceptions of melanoma as a non-serious condition was a particularly notable part of their experience because of the disparity with their own sense of their experience, their feelings and responses. This resulted in further complications in their feelings and sense-making. This was typified by Tony as feelings of anger and, for both, isolation. For Claire this also challenged the permissibility to take herself, her feelings and experiences seriously and to make sense of and to accept them:

I just think their perception is.....that because it's a surface cancer to start with its nothing really. You can almost flick it off as if it's a Coco Pop, and then it's gone. But it's not is it?

(Tony, 573-576)

His [melanoma] was really, really serious, obviously he died. So that woke everybody up at work, you know, god it can be serious. It *is* serious. Isn't it?

(Claire, 459-460)

This extract illustrates Claire's apparent seeking from the researcher validation for her feelings where this has been denied elsewhere. This lack of validation for Claire

was confirmed further by the rejection by others of her warnings or advice regarding sun behaviour.

All participants commented on their own underestimation of the severity of the meaning of the diagnosis, on both a practical level with regards to what the treatment would involve or in a more existential way. Not only did others around them underestimate of the severity of the condition, so too did they:

...and the one girl says “ooh that’s nothing then is it, it’s only skin cancer, at least it’s not like a bowel cancer” and I thought, “bloody hell you ignorant”But then again I thought melanoma wasn’t a cancer anyway.

(Tony, 164-167)

This underestimation resulted in surprise and a lack of preparation for the nature of the surgical procedures and the often discomfort, pain and/or distress associated with the experience. Dawn talks about her second excision, which she described as being the worst part of her experience:

Yeah, it was too hot in there and I could hear him throw my skin, my, “plop” it was like a steak being thrown in the rubbish bin. Which is most, I mean really, unpleasant.

(Dawn, 424-426)

Graphic descriptions of the surgery are common throughout the accounts of participants. The painful and unpleasant immediate and, occasionally longer term effects of the surgery are also frequently discussed:

It is horrendous not being able to shower you know, and erm, that was pretty dire..... you know, I'm a human being not an animal and trying to get up the stairs on your bottom backwards..... its horrendous.

(Mary, 161-168)

Tony described how he had deliberately sought out a specific melanoma support group, as opposed to a general cancer group:

Well the Macmillan one, erm, I felt was just a cancer group and the ones with like bowel cancer and breast or lung cancer and that type of thing, they believed that theirs was more important.

(Tony, 745-751)

Again this emphasises his need to be acknowledged and taken seriously. Other participants, however, expressed their desire or contentment for others to minimize the melanoma, finding this reassuring or meeting their wishes to deal with it and move on. In fact for these participants too much concern or acknowledgement of the condition was unwelcome or rejected:

I've found that I've had to sort of say to them....it's going to take a while to heal and it's alright so don't keep asking....I wanted to forget, I wanted to get the dressings off and let it heal.

(Lilian, 259-276)

This theme reflects the participants' making sense of the severity of their experiences. In spite of the positive prognoses associated with their diagnoses participants experienced a range of difficult emotions and thoughts. For some

participants the desire for others to take their experiences seriously (or not), and the perception of others about melanoma impacted upon this process.

2.4.2. Theme 2. Finding an equilibrium

Participants commented on the processes that they went through to restore, for themselves, a sense of normality or balance. At times, for some participants, this was an active process, where deliberate attempts were made in an effort to achieve this. At other times, existing resources were mobilised or perspectives taken without deliberate thought. This theme “Finding an equilibrium” is discussed now, within the sub -themes “Dealing with it”, “Perspectives on support”, and “In the context of what life dishes out”.

2.4.2.1. Theme 2a. Dealing with it

For some participants ‘dealing with it’ involved adopting a practical and pragmatic approach to the treatment, its consequences and longer term effects. Lilian, for example, talks in a matter-of-fact way about caring for her wound even when there had been unpleasant complications:

...and I went to the nurses twice a week but I had got to do it every morning myself so I showered it, washed it well and erm, used the steroid dressing after to dry it out then put this cream in and put a dressing on. So I did that every day for a few weeks.

(Lilian, 172-176)

The personal importance in seeking a positive outlook whilst trying to counteract negative thoughts seemed to be a part of Dawn's experience. Here, following her diagnosis, she speaks of trying to centre herself and retain a sense of reality:

....you know, "it's only, you're not dead!" So er, then I went off to [shopping centre] and had a cup of coffee as you do (*laughs*). I just thought I've got to do something that is a little bit normal and will get me back to, cos actually instead of going down the erm, your head going down the, erm, completely wrong way, bring yourself back to reality.

(Dawn 125-130)

In this extract the deliberate attempt to adapt outlook and response is evident, and is mirrored in some other participants too, where fighting against negative thoughts or the potential to become maudlin is discussed. An implicit, non-deliberate sense of positivity when making sense of and coping with the experience is also clear:

It's gone and it's done and it's away, it's finished with its not like I'm sitting there and I'm very thankful for that that I haven't got any long lasting effects from it. I'm grateful.

(Dawn, 323-325)

Remaining positive through comparisons with others was clear with some participants, drawing their attention towards their comparatively desirable conditions and prognoses:

You know that you can have them removed, it isn't like breast cancer or anything like that where you can... it must be terrible because you know it can be ongoing.

(Lilian, 237-240)

Minimising the experience was a further way of 'dealing with it' for some participants. This is illustrated not only in the content of their narratives but in their chosen language and use of laughter:

.....so spent 24 hours panicking, and, uh, he was very apologetic and it had been diagnosed as a melanoma, this mole *and that was it really*
[emphasis added]

(Mary, 31-33)

and I went back to the [hospital], for the second operation and that's when they dug it all out and skin grafted it all over. God it was painful
(*little laugh*).

(Claire, 47-49)

In both of these examples and throughout these two participants' accounts, in spite of the unpleasant emotions associated with the content, the participant attempts to take the emphasis from this with the addition of a phrase or laughter.

For Claire, this minimisation and the importance of down-playing in spite of the significance of the impact upon her, contributed to her approach to coping by blocking it out. Claire had been attempting to manage the feelings associated with her experience by "keeping it together", keeping it to herself and not talking about it and by rejecting the desires of others to share experiences:

Erm, to be honest with you I've never talked about it before, this is the first time (*laughs*) so don't know why I'm like this [upset], it's stupid, isn't it....I've just sort of, go with the flow and get on with it.....

(Claire, 384-393)

2.4.2.2. Theme 2b. Perspectives on support

For all participants their perspectives of feeling supported had a role in their melanoma experiences, and restoration of balance. For some, the value of their friends and family in supporting them were integral to their dealing with this experience:

My husband has been a great support, probably been together so long now he knows exactly what to say and when to say it and when I need to be left alone.... But yes, he does chivvy me along a lot - you can do this "you're fine".

(Mary, 201-206)

For Mary, feeling understood and having the type of support that works for her was clearly important, especially as she then goes on to reflect on how different she imagines the experience would be for someone without this support:

How people manage if they are on their own, it must be just devastating as everyone gets their black days they don't need this sort of scare to get them do they and that must be pretty galling if there is nobody there.

(Mary, 312-314)

Being 'in it together' was a prominent theme emerging from Lilian's account as well. This involved the practical, shared approach to dealing with this situation (as with all situations) with her husband, but also in this case with professionals, where there is a clear indication that Lilian felt part of the process with those involved in her care:

He couldn't make up his mind but he didn't want to scrape it like
he did the others, we [emphasis added], knew it was a bit different.

(Lilian, 60-61)

He [consultant] did say there were no signs of the melanoma, when
I went for my follow up, but we [emphasis added] have got to be
careful because it can come up....you can get it in other places.

(Lilian, 80-81)

Participants all spoke about the value of professionals in the process where they felt
supported and cared for by them. For some, the practical reassurance of regular
check-ups by the Clinical Nurse Specialists was a priority:

That [end of follow up appointments], I sort of had a thought you
know because it's quite, er its quite good to know that someone's
going to have a look over you regularly.

(Lilian, 291-292)

Whereas others valued too, the emotional support that was offered:

Yeah, I felt like I could tell [CNS] anything I was worried about.

(Anne, 326)

For Tony and Claire, their experience appears punctuated by a perception of a lack
of appropriate support to meet their needs. This could be considered as being driven
by a lack of understanding by those around them, particularly for Claire,
demonstrated here when talking about her friends:

....when she came round she goes “what you doing with your foot Up?” and “you should be up and you should be dressed with your make up on” and I’m thinking I can’t, I can’t even move never mind get dressed. (Claire, 405-411)

Tony is more explicit in his perception that his needs for support were not initially adequately met, particularly by professionals involved in his care, and by other support agencies, when he first sought it:

....because I was that upset at the time I did say to my wife that “sod it, if she [CNS] can’t be bothered to ring me and see how I am then I am not going to bother going to my three monthly appointments.... I was really angry. I was more angry that I hadn’t had any support as in, I tried.

(Tony, 349-357)

This strength of emotional response to a perceived lack of support indicates the importance to Tony of it being available when needed. The importance to him of feeling supported by being having his needs acknowledged and valued by professionals was notable in its absence.

2.4.2.3. Theme 2c. In the context of “what life dishes out”

For four participants in particular their experience was seated within the context of other life experiences, both current and historic. In spite of the expressed distress at these experiences, these four participants all refer to other difficult life experiences when making sense of their experience with melanoma, providing them with

perspective and defining their ability to cope and manage. For example, after discussing a series of traumatic events throughout her life Lilian reflects:

You think whatever life dishes out with you, you have got to
get on with it, suppose I'm a bit hard in that respect.

(Lilian, 252-254)

Anne too considered lessons she'd learned from dealing with difficult situations throughout her life to have influenced her perception of her melanoma experience and her ability to deal with it:

I blocked things off [when referring to an historic event] else I would
have never slept at night, and I think that is what I do with all this now.
Clear it out your head and don't worry about it.....and that's how I
cope now.

(Anne, 161-165)

Dawn refers to her melanoma as being part of a difficult time overall for her, of which the melanoma was not the most important part. Furthermore, she discusses it within the context of other health conditions:

I have had ill health throughout my life so I think a little knock of,
you got to have a little operation and away you go is perfectly easy
to cope with

(Dawn, 194-197)

Anne and Lilian, as well as Mary, place their melanoma experiences within the course of increasing age:

Well, I think you get to a stage really in life or an age, where, you know these things start happening. People start falling apart (*laughs*).

(Mary, 115-116)

You get to my age and you've had all sorts of things and nothing seems to bother you ,you expect it really don't you as you get older.

(Lilian, 119-120)

'Finding an equilibrium' or a state of balance in the wake of, at times, difficult experiences and responses was important for all participants. Participants discussed the specific ways in which they sought to 'get on with it'. Perspectives on the support available and the positioning of the experience in the context of "what life dishes out" were important contributing factors to this process.

2.4.3. Theme 3. A chapter closed?

All participants reflected upon the impact that a diagnosis of melanoma had on them, and whether and to what extent they felt as if this experience had changed them and their lives. Whether this experience was a chapter that could truly be considered closed, or an experience that is continuing is discussed below under the sub-themes "It's in the past", "Expert mole checker" and "Incorporating the experience in to a sense of self".

2.4.3.1. Theme 3a. It's in the past

Some participants emphasised placing their experiences of melanoma in the past, with this being something that has been dealt with and no longer a concern. For them, their melanoma was conceptualised as being within the wider scheme of life:

Yes, yes so I feel like that's another chapter now and um, gone. Wait for the next.

(Lilian, 451-454)

And it's gone. That period has now gone and you're on to the next bit. But it's only the ups and downs of life.

(Dawn, 251-253)

For these participants, this was accompanied by an assertion that the experience had not resulted in an unacceptable change to their lives or their lifestyles. Anne, who upon receiving her diagnosis was devastated by thoughts that she would no longer be able to go on holiday had been able to reconcile sun safety with travel abroad and was still holidaying. Similarly, Dawn speaks about still being able to do what is important to her:

As long as I can carry on with a lot of my life which I can, I might not be able to sit in the sunshine or sunbathe for long now but I hadn't for years to be quite honest but I wanted to swim in the sea and I can swim in the sea so.....

(Dawn, 212-215)

All participants, however, commented on the ongoing impact and changes that have resulted from the melanoma. For some the emphasis was on necessary, practical behavioural changes:

....but I do think about my skin, I do cream up all the time, erm, don't sit in the sun, sit in the shade and yeah I do think about it but not as cancer.

(Anne, 239-241)

The ongoing need for vigilance and checking of their moles and bodies was also mentioned by all participants; this is discussed below, theme 3b 'expert mole checker'.

In spite of conceptualising their melanoma as being in the past, in some way for all participants, the chapter is not completely closed. For Claire and Tony this is even more marked, with both of these participants strongly being influenced by their melanoma now. Claire's ongoing resulting health difficulties, unacceptable changes to her appearance, pain and fear of reoccurrence mean that her melanoma experience is something that she continues to live with, and try to come to terms with. Similarly, Tony describes how for him the experience is not in the past, describing his difficulty in accepting that the melanoma has gone:

cos I've got to learn to live with it now suppose. And I haven't got it now have I. I've had melanoma, I've had skin cancer, I haven't got it now....I still feel it's dormant in the body and I'm just waiting for it to flare up and try and catch you out. I think melanoma is a bit sneaky.

(Tony, 869-873)

Tony is caught between knowing that the melanoma is gone and that there is a positive prognosis, but being unable to be reassured and accept this. For Tony and Claire this is considered an ongoing, life changing experience, of which the chapter is certainly not closed:

So although she said to me, erm, she reinforced it three or four times that the chances of you getting it again are....my life has changed forever now.

(Tony, 521-523)

2.4.3.2. Theme 3b. Expert mole checker

For all participants ongoing vigilance of their body was a part of their life after melanoma. For some this was a practical incorporation in to their lifestyles, based upon an understanding of the need for it. Fear, anxiety and concern for reoccurrence was a driver for Claire, who frequently referred to her paranoia about moles. This fear with regards to re-occurrence is strongly shared too by Tony, who expresses an absolute belief in it. Although less prominent, some anxiety about reoccurrence was shared by Anne and Mary who also described her tendency towards increased vigilance, but within the context of her perception that some anxiety is to be expected and normal:

You do tend to go into overdrive like “did I have that mole there before?”.

(Mary, 130)

Lilian talks about this as being a necessary and practical task which she does not consider burdensome:

It makes me check myself more often and my husband will check my back for me. I'll say, you know after a couple of weeks I'll say time's gone, I'll say just check these now.

(Lilian, 337-339)

Noticing others' moles and becoming an 'expert mole checker' for others' as well as selves was a common experience for participants:

You're more aware of your body I think, yeah..... I'm aware for other people as well as myself (*laughs*), I'm like "what's that?".

(Anne, 343-350)

....and all their [children's] friends, so they're all coming for me to have a look at their skin. It's like a little walk in centre (*laugh*) for checking moles.

(Claire, 181-191)

For Claire particularly, checking of others was accompanied by her concern for them and her desire to advise and warn them of the risks. It is important to note that this may be a greater concern for Claire, beyond that of most of the other participants, due to her discovery of two melanomas within six months of each other.

2.4.3.3. Theme 3c. Incorporating the experience in to a sense of self

For some participants their experiences of having melanoma seemed to impact in some way upon how they saw themselves; their sense of identity. Others were clear that the assimilation of their experience did not involve this. Four participants spoke

about changes to their feelings of immunity or indestructibility whether in relation to mortality generally or susceptibility to illness:

...not feel like I'm immune from certain illnesses which I kind of had because it, you know if it was my heart or blood pressure I might have expected it or even dementia you know but never cancer.

(Dawn, 297-300)

For Tony, it seems as though his experience of melanoma has become a core part of his existence and has shaped his identity. Being part of a 'melanoma community', a minority group of people who understand and share his experience is important to him. This sense of belonging to this community and the value and importance of this new found part of his identity is indicated here, where Tony is talking about being a participant in this research:

So, this group [Facebook support group] they're really interested in, and think it's fantastic that someone is actually spending a bit of time on our little melanoma people.

(Tony, 497-499)

Contrastingly, when talking about her experiences, Mary speaks of her rejection of an illness identity, a desire to separate herself from other people who may share her experiences:

When I went to, it's the [department name] isn't it? I felt like I had been asked to join a club that I didn't want to belong to (*laughs*) it was almost as if we all knew in the waiting room, the reception, what we were all there for, but I didn't want to be there. "You're poorly, I'm not".

(Mary, 248-252)

For Tony this immersion in melanoma extends to awareness of anything melanoma related, for example media coverage and participating in campaigns. Furthermore it is evident that Tony, and Claire too, have actively researched and educated themselves in the area months after treatment, and in Claire's instance months after the end of her follow up appointments:

I just, I like to just to keep, keep on reading about it. Er, I don't know,
I don't really know why. I'm just interested now to be honest with you,
I'm interested and looking, thinking, you know.

(Claire, 628-362)

For Claire, this compulsion to research and learn seems driven predominantly by fear. This too could be said about Tony, educating himself in a desire to better 'arm' himself against the "sneaky melanoma". However, the 'expert' knowledge and the acquisition and sharing of this knowledge as part of the integration of the experience into his identity is also clear.

Scarring acted as reminder of their experience for some participants. For most this was considered an acceptable consequence:

But everything else is get on with life, if I've got a scar I've got a scar,
just get on with it.

(Dawn, 211-212)

Although agreeing there are worse things than scarring, Mary acknowledged the difficulty in accepting the appearance of the scar. Claire too has found the changes

to her appearance particularly hard. The strength of her feelings towards the changes to the appearance of her foot are so strong that she appears to now reject her foot as a part of her:

Yeah, it's all numb all around here, except when you touch that part here, that's a killer, all there, these toes.....to be honest my foot doesn't feel like it's my own any more, feels like it's someone else's. Ugly looking thing it is, its horrible (*laughs*).

(Claire, 341-344)

Claire spoke also of how she had found herself to be a “nervous wreck” since discovering her melanomas. Her frequent use of pejorative terms about herself, her anxiety and concerns indicate the difficulties she is experiencing in accepting the changes to her sense of self. Claire communicates her anxiety that she is perceived as, and fears herself to be, “crackers”, “mad” and a “barnpot” as a result of the feelings elicited by this experience:

.....cos I just think I'm going (*laughs*) mad if I keep on checking, thinking that's one changing.

(Claire, 141-142)

God, I sound like a mad woman.

(Claire, 274)

Although divergence exists within this superordinate theme with regards to how much impact melanoma still has on each participant's life, to some extent for no participant is the chapter truly closed. Participants continue to find themselves

vigilant to checking moles, not only on their own bodies but of other's around them too. For some the experience has had a long lasting effect on the sense of self.

2.5. Discussion

This study explored the experiences of people who had been diagnosed with and treated for malignant melanoma at stage I or II. Its aim was to gain a detailed perception of experiences of melanoma which may be used to better understand and inform clinical practice.

Three themes emerged from the data and these will be discussed with relation to existing literature before consideration of the clinical implications of the findings and the study limitations.

2.5.1 Discussion of the findings

2.5.1.1. Theme 1. It is serious. Isn't it?

This theme considered the tension between whether the experience of having had melanoma was conceptualised as a serious life event or not. Previous research has indicated the presence of emotional responses and psychological distress following a diagnosis of melanoma (Kasparian *et al.*, 2009; Taylor, 2009; Winterbottom & Harcourt, 2009). This too was true for participants in this study, who described shock and in some instances devastation. The in-depth, qualitative approach to this study afforded closer exploration of this experience and indicates that, in particular, the incongruence of the severity of the diagnosis with the appearance of the mole and

the use of the word “cancer” seem important mediators to these reactions for these participants. Kneier (1996) has previously discussed his experience of working with people with melanoma and the contrast between those that believe it is “just skin cancer” and those that believe “cancer” is a death sentence. Consideration of melanoma as a potential threat to life was a shared experience among participants. Cornish *et al.* (2009) also reports melanoma patients expressing fears about death following diagnosis. For those with a high risk of reoccurrence, these fears may persist for years after treatment (McCloone *et al.*, 2012). There existed divergence within the sample with regards to a desire to have their melanoma diagnosis and experience taken seriously, or not. For those that did, it was an additional source of stress when others did not take them seriously. McCloone *et al.* (2012) report participants’ experiences that friends were able to offer little empathy with regards how dangerous the condition may be.

2.5.1.2. Theme 2. Finding an equilibrium

Participants participated in a process of ‘dealing with’ their experiences of being diagnosed with and treated for melanoma in order to restore for themselves a sense of emotional balance. It was apparent that they employed different methods in order to do this. Previous research examining coping styles in patients with melanoma has found active, problem-focussed coping strategies are more beneficial for adjustment than avoidant coping strategies (Kasparian *et al.*, 2009). Optimism, hope and expression of emotions are also indicative of successful coping (Kneier, 2003). Psychological resilience may be fostered by adverse life events (Seery, Holman & Cohen-Silver, 2010). Participants’ placing of their experiences with melanoma within

the context of “what life dishes out” may mediate their ‘finding an equilibrium’ in this way as well.

Comparison with others perceived as worse off was elicited as part of some participants’ ‘dealing with it’. This facilitated increased self-esteem for Winterbottom and Harcourt’s (2004) sample, as they realised they could be in a worse situation. Social Comparison Theory (Festinger, 1954) posits that people make sense of their experiences through comparisons with others. When these are downward comparisons the consequence is to feel better about one’s own situation. Winterbottom and Harcourt (2004) also reported participants’ minimisation of their experience in their sample, as is the case for some participants in this study.

The presence of social support has previously been considered critical in the role of psychological adjustment to melanoma (Dirksen 1989; Sollner *et al.*, 1999). Social support may act as a buffer at times of stress (Cohen & Willis, 1985) and interact with coping styles as discussed above, to enhance coping (Sollner *et al.*, 1999). Participants in this study all referred to the importance of support for them in seeking ‘equilibrium’.

2.5.1.3. Theme 3. A chapter closed?

Participants’ experiences of melanoma being perceived as in the past, as a chapter closed, or as an ongoing experience is the final theme emerging from the data. The majority of existing literature has focussed on reactions to diagnosis, with emphasis on psychological distress. Long-lasting effects or persistent changes have received

little attention. Oliveria *et al.* (2013) discuss both positive and negative longer term effects of having had melanoma; for example positive and negative changes to relationships, improved appreciation for life and ongoing, negative physical and psychological side-effects. Participants' experiences of integrating their experiences in to their sense of self, has not before been investigated with regards to survivors of malignant melanoma.

2.5.2. Clinical implications

This research has indicated that for some patients receiving a diagnosis of melanoma is a difficult experience. Current guidance advocating the presence of a Clinical Nurse Specialist and a companion at diagnosis is clearly endorsed by the findings of this study. Awareness and sensitivity to when patients may need further emotional and psychological support, without pathologising a normal reaction to shock is advocated. National Institute for Health and Clinical Excellence (NICE) guidance (2006) indicates the need for Clinical Nurse Specialists to be trained to identify and respond to patients' psychological support needs within skin cancer multi-disciplinary teams.

An awareness of the difficulties that patients may have in understanding whether their experience is serious or not and the impact that this may have in accessing both social and professional support, is also indicated for professionals. A conversation with patients, at diagnosis and at follow up, about the sense that they have made of their diagnosis and treatment may be beneficial in assisting them to communicate their needs.

The experiences, responses to and sense-making of having had melanoma is indicated as differing on an individual basis. Clinicians supporting patients with melanoma should be sensitive to this and be aware that a person's adjustment to the diagnosis and treatment is more likely to be based on their individual perspective and ways of coping than on an objective, medical indicator.

A more specific implication of this research is the consideration of the use of the term "Macmillan" at diagnosis. For participants who mentioned this in their accounts, this word provoked or contributed towards their feelings of fear about their diagnoses.

2.5.3. Methodological limitations

IPA methodology emphasises small samples where detailed, idiographic examination of participant experiences can occur. However, due to its use of small sample sizes IPA does not pertain to be able to make generalisations to the wider population.

The participants in this sample were all White British and opted in for participation in the study. This may be a source of bias, with those choosing to participate having certain motivations to do so. Only one participant in the sample in this study was male. With some research indicating gender differences in adjustment to melanoma (e.g. Hamama-Raz, 2012), this under-representation may have acted as a source of bias. The recruitment procedure may also have introduced bias to the sample. Not all melanoma patients who met the inclusion criteria necessarily have follow up appointments conducted by the CNS's. In this way, participants that may have had a

different experience of the treatment and follow up were not invited to participate in the study.

Recruiting more participants to the study may have enriched the findings, although the breadth and depth of experience elicited by the six participants in this sample provided rich data with clear evidence of divergence and convergence.

2.5.4. Areas for future research

This topic area would benefit from further qualitative research exploring participants' experiences with different samples, from different demographics and recruited from different NHS services. This would add to the understanding of the experience of having melanoma.

This study was designed to elicit participant experiences broadly and from across the melanoma trajectory. Future qualitative research studies looking specifically at different points of the journey or upon specific aspects (e.g. experiences of support, experiences of younger patients specifically, or experiences of diagnosis), will act to contribute an even more detailed insight into the experiences of people who have had melanoma. Future research may also focus specifically on the longer term impact, or impact upon the sense of self as a result of these experiences. Improved understanding of the specific experiences and support needs of people who have had a diagnosis of melanoma is increasingly important when considering ongoing rises in prevalence and the numbers of younger people affected.

2.6. Conclusion

This study has explored the experiences of participants who have had a diagnosis of and treatment for malignant melanoma. Using an Interpretative Phenomenological Analysis methodology, six participants' accounts of their experiences were analysed. Participants' experiences were characterised by a tension between whether receiving a diagnosis of melanoma, the treatment and on-going consequences were a serious life event or not. Participants discussed also the process of seeking to restore balance for themselves before considering the ongoing impact, and longer-lasting effects of this experience. Future research to understand in even greater depth, as well as breadth, the experiences and support needs of people who have been diagnosed with melanoma will further contribute to best inform professionals and services.

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Chapter 3 – Reflective Paper

A chapter closed? Reflections on my research journey.

Paper not intended for publication.

Overall chapter word count excluding references: 3020

3.1. Introduction

The final chapter of this thesis is a reflective account of my research experience. It will follow my experiences of being a researcher; initially by reflecting upon the conception of the research idea and the development of my relationship with the topic area. The integral role in this of meeting and interviewing the participants, including my responses to their accounts and experiences will follow. This paper will conclude by considering whether for me, too, like the people who participated in this research, the submission of this thesis represents a chapter closed.

In line with the reflexive practice integral to an IPA approach, this paper will make reference to thoughts, feelings and beliefs recorded in my reflective journal throughout the research. Reflexivity was also enhanced by means of a 'bracketing' process, designed to elicit pre-existing attitudes, beliefs and assumptions. These too will be considered in this paper.

3.2. The conception of the research and my relationship with the topic area

I did not set out to research the experiences of people who had been treated for melanoma. My research interests when starting this thesis centred on adjustment to, and making sense of, what may be conceptualised as 'catastrophic' health events, such as an acquired brain injury. I knew also that my research interests lay within qualitative methodologies, particularly those that afforded a detailed understanding of an individual's experience and perspective. This paralleled my emerging clinical interests discussed later in this paper, see 3.4. The process of developing my research

ideas and formulating the research proposal for this study was, at times, convoluted and it was with melanoma that I 'ended up'.

Exploration of my very early ambivalence for the topic area has been an interesting and important process for me. Reference to my reflective journal at the time indicates a lack of excitement for the subject, confusion as to whether it was worth conducting research into and reflections on friends' and acquaintances' responses when I spoke about my research intentions. It seemed to me that other people shared my uncertainty, and I found myself feeling like I needed to justify and explain my reasons for choosing to conduct this research. Retrospectively, now that the data collection, analysis and interpretation is complete, the parallels between my own early ambivalence and the experiences of the participants themselves are apparent. For them, the question "It is serious, isn't it?", resonated throughout their accounts, influenced by their own preconceptions and the attitudes and opinions of others. I can see that a conflict existed for me too, where my preconceptions about skin cancer and melanoma and perhaps the seriousness, and worthiness affected my feelings towards the topic area.

Skin cancer and melanoma, specifically, had not been a condition that I had afforded much time to thinking about prior to undertaking this research. I had never explicitly thought that skin cancer was not serious, or unimportant, but the very fact that I had not even considered whether I believed it to be or not, in spite of a definite awareness of it, indicates an implicit disregard. This attitude, although not fully in my

awareness at that time, was clearly an important contributing factor to my early ambivalence.

The knowledge that I had about skin cancer had been influenced heavily by the strong preventative message conveyed to me through the media, my family and wider society, since I was a child. Skin cancer prevention has been the focus of health campaigns (for example, Cancer Research UK's "SunSmart" campaign), and is a health priority due to rapidly increasing incidences (Cancer Research UK, 2014; NICE, 2011). In this way the emphasis for me had been what causes skin cancer and how to avoid this. This differs from my perspective of other cancers where the emphasis for me, was on the devastating consequences and severity of a diagnosis. As I developed my knowledge in the area my initial ambivalence was replaced by an interest in further exploring the experiences of people affected by a melanoma diagnosis. Perhaps, like Tony, who refers to people with melanoma as being an "under-studied" group, I began to realise the value of 'giving a voice' to and better understanding these experiences.

My preconceptions of melanoma being embedded within the context of sun exposure, sun bathing and sun beds impacted upon my assumptions of the experiences of the participants. These were most clearly elicited during the pre-interview 'bracketing' process where I explored my presumptions about what the participants may recount of their experiences. Bracketing refers to a reflexive practice whereby the researcher attempts to identify areas of potential bias within themselves and to "bracket" (but not disregard) them so as to minimise the influence

upon the research (Ahern, 1999). I had anticipated that tanning, and the impact of tanning upon body image, would be a part of the experience described by participants in this research. Furthermore, I had wondered whether attempts at making sense of their experiences would involve a certain amount of blame and self-recrimination about how their own behaviour had contributed to their developing melanoma. I recognised that not only had personal and societal influences been integral to the construction of these beliefs for me, but also my own relationship with tanning and sun behaviour. In the past I had experienced a dissonance between wishing to be tanned, because of my belief that it was more attractive, and the knowledge that it was 'bad' and unhealthy to do so. It was apparent that when placing myself in to a position of receiving a diagnosis of melanoma, I could anticipate an attribution to previously ill-advised behaviour, and be conscious of my own role in the causation of this. It was important for me to gain this explicit awareness of these beliefs so that I was free to be able to listen to participants' stories without imposing my own prior conceptions upon them. Finlay (2008) refers to the IPA researcher's aim to "reflexively restrain" pre-understandings so that the shift of focus remains upon the participant's lived world. In this instance my assumptions were not accurate and this was not an important part of participants' experiences in this study.

My relationship with melanoma as my empirical paper topic developed significantly from conception. It was the process of interviewing participants, however, when I was able to engage with their lived experiences, that was most influential in developing my conviction for researching this topic area.

3.3. My experiences and reactions to the participants and their stories

It might be considered inevitable when conducting research that involves such immersion in a participant's world that some sort of response or reaction will be invoked in the researcher. For me, this involved different emotional responses at different times, and provoked thoughts and reactions which impacted upon my beliefs and perceptions. It was these moments, and the opportunity more generally to hear the participants' stories that was the most valuable part of my research experience, and that that most marked the shift in my relationship with the topic area.

Overall, the interviews afforded me a greater understanding and appreciation of the potential impact that melanoma can have. I noted my own surprise at the descriptions and consequences of the surgery in particular. The fact that this had caused me surprise, and on one occasion to flinch as a participant described her experiences of the surgery, made me realise even further my underestimation of the severity of the implications of a melanoma diagnosis. By this stage I had a theoretical knowledge of what excision would involve based upon my meetings with the skin cancer Clinical Nurse Specialists and my own research into it, and yet, to hear it from the perception of the participants still affected me. In this way, again, my own experience mirrored the participants'; "it is serious, isn't it?".

It was the final interview with Claire that elicited the strongest emotional reaction in me, most probably because it was her who seemed to be experiencing the most difficulty and distress. Beyond an empathic response to her distress, I was affected

by what I perceived to be Claire's sense that it was not acceptable for her to feel the way that she did. It seemed that for her, to do so would be a weakness, and an unacceptable burden upon those that were around her. I was aware during the interview and later during transcribing and analysis that Claire may have been in some way testing me through the interview, assessing whether she could trust me to hear and accept her and her experiences, and then seeking from me, and the interview process, validation for herself. For me, the impermissibility of being affected by the diagnosis and treatment seemed the most serious consequence of the "it is serious, isn't it?" tension. I wondered how different her current emotional situation would be should this aspect of her experience be different.

The resilience of some of the participants resonated with me during this research. As a Trainee Clinical Psychologist I am only really afforded the opportunity to be permitted into the psychological world of people who are experiencing an unacceptable level of distress. Opportunities to gain such in-depth perspectives of 'successful' adaptation to stressors or integration of experiences are less frequent, and I did notice an enjoyment and appreciation for hearing these perspectives. This was perhaps most clear during my interviews with Lilian and Anne. I noticed my admiration and respect for these participants, not only how they had dealt with having melanoma but what I had gleaned about their overall approach to life and how they spoke about previous traumatic experiences. I was conscious of how hearing Lilian's story, in particular, affected my feelings and thoughts about previous participants' experiences. This allowed me to be mindful of the potential impact upon

my interaction with, and interpretation of, her and subsequent participants' accounts of their experiences.

Being able to hear and consider the stories of coping, adjustment and resilience allowed me to reflect on my own approaches to dealing with stressors, both helpful and unhelpful. This awareness and thoughtfulness is hopefully part of an ongoing process for me of making changes for myself to improve my responses to stressful situations.

When I interviewed Tony, I felt engaged with him and his experiences, and I empathised with the frustrations, concerns and fear that he conveyed and that was so obviously important for him to share. However, during the transcription and data analysis process, some different responses were elicited in me. I found myself becoming frustrated with him, and at times angry with certain aspects of his perspectives and the narrative of his experiences. These were new feelings, that were not present during the interview itself and it was important that I tried to make sense of them before continuing with my interpretation of Tony's experiences. By considering carefully what precisely about Tony's account had resulted in these feelings, I was able to identify in my own, and my family's narratives and schema, a series of discrepancies. For example, I had become attuned to Tony's sense of being let down, hard done by, and de-prioritised within the melanoma treatment process. This is contradictory to what would be considered the 'correct way of being' in my family, where assertion of own needs, and expressed belief in own importance/value is in fact, from my perspective at least, de-prioritised and not the 'done thing'. This

reflection highlighted a personal conflict for me, and I recognised that this probably played a part in the elicited feelings of frustration and irritation towards Tony. This insight, reviewing of the notes I took immediately after the interview and re-immersing myself in his account from his perspective, allowed me to return to an interpretative process which was less impacted upon by my own personal bias.

It was during the interview with Tony also that I was most aware of a potential conflict between my roles as a researcher and as a clinician. This was particularly the case with Tony perhaps because of what I perceived to be clear and frequent, what would be defined by a Cognitive Behavioural Therapy (CBT) perspective as 'unhelpful thinking styles' (e.g. Williams & Garland, 2002). At times, I noted a desire or inclination to counteract or comment on something he had said from this position. Identifying these processes within myself and maintaining a reflexive stance with regards to it, helped me to stay within my role as a researcher and not accidentally place any unhelpful impositions upon Tony's or, in fact, subsequent participants' accounts. I found that as the interviews progressed there were fewer inclinations to intrude in this way, and I was more able to concentrate on working fully to understand the participants' experiences as a researcher. The conflict arose once more with Claire during the final interview where I was drawn to want to help her and felt dissatisfied with the interview, not from a researcher's perspective but, from a clinician's perspective, or perhaps in fact, a more general human perspective.

I noticed also the potential impact that minimisation of the experience, present in some participant's accounts, might have had upon their narratives of their

experiences and my experience of them. This was complicated by a sense of frustration at times when I perceived participants to be less forthcoming with aspects of their experience. At the same time I had an appreciation of this itself being an important part of their experience with regards to dealing with, and making sense of it.

I have reflected upon the impact that those participants who most touched me because of the emotional responses they elicited in me may have had during the analysis process. I was aware of the potential for their voices to be heard louder than others' because of this, and therefore affect the validity of the analysis in terms of representing the perspectives of all the participants. With this awareness I was careful to ensure I adhered to the qualitative quality assurance recommendations (Yardley, 2000) of rigour and transparency with regards to the analysis process, and to consider the contribution of each participant within all of the themes generated from the data. In doing so I could ensure that the overall themes were representative of all participants, even when divergence existed, or that the nature of the expression of the themes differed between participants.

3.4. Continuing my research journey –the impact upon my sense of self as a Clinical Psychologist

It was an interest in seeking to understand individual experience and interpretation of experience that influenced my desire to undertake research using an IPA methodology. As a clinician my interests and inclination lay with seeking to understand a client's situation through the sense they made of it, from their unique

interpretation, rather than to impose upon them pre-existing theoretical or conceptual assumptions. This is akin to constructivist ideas that I had been introduced to prior to starting my clinical psychology doctorate training (e.g. Kelly, 2003). Integral to these schools of thinking is the adoption of an awareness of one's own beliefs and constructs, and the importance of reflexivity to consider these (Bannister, 2003). This too, is a central process for an IPA researcher.

Conducting this research has contributed to the development of my identity as a Clinical Psychologist in a variety of ways. It has highlighted the intrinsic value of putting aside one's own, or wider societal or theoretical presumptions about what may be occurring for a client and taking the time to truly seek to understand their perspective. My experience as a Trainee Clinical Psychologist has meant that a 'pressure' to facilitate change and ensure outcomes for clients effectively and quickly may preclude a commitment to, and opportunity to, truly listen. When listening in a therapeutic setting, competing cognitive processes (such as thinking about formulation, thinking about how to present an idea, or, indeed a requirement to stick to an agenda or particular topic) can all compromise this process. This is something that I will continue to navigate and seek to make more sense of as I continue my development as a Clinical Psychologist.

This learning may have been particularly pertinent for me considering my own pre-conceptions of melanoma. The experiences of the participants were, at times surprising for me and I might anticipate would be for others too. Furthermore, it was clear to me that it was not easy to anticipate or understand the various responses

and reactions of the participants without specific consideration of the unique internal and contextual processes of each individual. For example, in spite of overall objectively similar treatment pathways and prognoses, the psychological reactions seemed to be different within each participant. This is similar to Lazarus and Folkman's (1984) model of stress which emphasises the appraisal of a situation as being the most important factor in understanding psychological adjustment and responses. This too, may be applied to all people in all circumstances, where it is not sufficient to consider any particular event, interaction or experience to be predictive of an outcome, but instead the appraisal and sense-making that accompanies it.

The introduction to a new area of work is also an important part of continuing the research journey for me. I had not worked as a psychologist within a physical health setting before and this has opened a new area of interest to me that I will pursue to further my interest and my experience with it.

3.5. Conclusions

My research journey through implementing and preparing my research for submission has provided me with an opportunity to reflect upon how I would like to continue the lessons learned through this process, across several key areas of development. It has given me a clearer sense of how I would like to integrate the things that I have learnt into my clinical practice as well as giving me a stronger sense of my research interests. Furthermore it has impacted upon my learning about myself which I will be able to take forward to contribute to my own personal, as well as

professional development. In these ways, this thesis submission represents a chapter for me that is not closed at all.

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Appendices

Appendix A. Author instructions for the *Journal of Psychosocial Oncology*

Journal of Psychosocial Oncology

ISSN

0734-7332 (Print), 1540-7586 (Online)

Publication Frequency

6 issues per year

Instructions for authors

Aims and Scope:

Here is your single source of international integrated information on providing the best oncology psychosocial care possible from the many disciplines involved in care and research of those influenced by cancer. The *Journal of Psychosocial Oncology* is an essential source for up-to-date clinical and research material geared toward health professionals who provide psychosocial services to cancer patients, their families, and their caregivers. The journal—the first interdisciplinary resource of its kind—is in its fourth decade of examining the influence of a cancer diagnosis on the patient, their families, and their caregivers, hypothesis testing, the effectiveness of interventions, the application of theory, and program evaluation research on critical areas of cancer care. Implications for future research and clinical practice based on the findings presented are encouraged.

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Appendix B. Quality appraisal checklists – quantitative methodologies

Checklist adapted from NICE (2012) Quality assurance checklist for quantitative studies.

Intervention quality	Score 2,1,0	Comments
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1. Is there a clear rationale for the intervention?
2. Is there a clear description of its content (i.e. enough for replication)?
3. Has the total intervention time been reported?
4. Have the therapists been trained in implementation of the intervention?
5. Is there a treatment manual and evidence of adherence?

Population (external validity)

6. Were the subjects asked to participate in the study representative of the entire population from which they were recruited?
7. Were those subjects who were prepared to participate representative of the entire population from which they were recruited? (D and B)

Allocation to intervention (risk of selection bias)

8. Was a control group used?
9. Was allocation to intervention and comparison/control randomised?
10. If not randomised, was significant confounding unlikely?
11. Were comparisons/controls appropriate?
12. Was the allocation concealed?
13. Were participants or investigators blind to exposure and comparison?
14. Were other interventions similar in both groups?
15. Were all participants accounted for at study conclusion?

Outcomes

16. Were outcome measures reliable?
17. Were all outcome measurements complete?
18. Were all important outcomes assessed?
19. Were outcomes relevant?
20. Were there similar follow-up times in exposure and comparison groups?
21. Was follow-up time meaningful?

Analysis

22. Were there any differences between groups in important confounders at baseline? 2 if no
23. Was intention to treat (ITT) analysis conducted?
24. Was the study sufficiently powered to detect an intervention effect (if one exists)?

25. Were the estimates of effect size given or calculable?
26. Were the analytical methods appropriate?

Total Score (out of 52)

Percentage

Appendix B. Quality appraisal checklist – qualitative methodologies

Checklist adapted from NICE (2012) Quality assurance checklist for qualitative studies.

Intervention quality

Score: 2,1,0
Comments

1. Is there a clear rationale for the intervention?
2. Is there a clear description of its content (i.e enough for replication)?
3. Has the total intervention time been reported?
4. Have the therapists been trained in implementation of the intervention?
5. Is there a treatment manual and evidence of adherence?

Qualitative methodology

6. Is a qualitative approach appropriate?
7. Is the study clear in what it seeks to do?
8. Are underpinning values/assumptions/theory discussed?
9. How defensible/rigorous is the research design/methodology?
10. How well was the data collection carried out?
11. Is the role of the researcher clearly described?
12. Is the context clearly described?
13. Were the methods reliable?
14. Is the data analysis sufficiently rigorous?
15. Is the data 'rich'?
16. Is the analysis reliable?
17. Are the findings convincing?
18. Are the findings relevant to the aims of the study?
19. Are the conclusions adequate
20. How clear and coherent is the reporting of ethics?

Total score (out of 40)
Percentage

Appendix C. Staging and grading of malignant melanoma²

The stage of a cancer is a term used to describe the size of the cancer and whether it has spread.

Knowing the stage of your cancer helps doctors decide on the best treatment for you. The staging system used for melanoma is the American Joint Committee on Cancer (AJCC) system. This uses the TNM system.

- **T** stands for **t**umour. This is based on the thickness (depth) of the melanoma using Breslow thickness. It also looks at whether the melanoma is ulcerated. A melanoma is said to be ulcerated if the layer of skin covering the melanoma cannot be clearly seen.
- **N** refers to whether the melanoma has spread to the lymph **n**odes (sometimes called glands).
- **M** is whether the melanoma has spread to other parts of the body (secondary or **m**etastatic cancer).

The AJCC system combines information from the TNM system to group melanomas into an overall number stage (stage 1-4).

Stage 1 melanoma:

All stage 1 melanomas are no more than 2mm thick and have not spread beyond the skin.

Stage 1 melanoma can be divided into:

Stage 1A: The melanoma is 1mm thick or less without ulceration.

Stage 1B: The melanoma is 1mm thick or less with ulceration OR between 1.01mm and 2mm thick without ulceration.

Stage 2 melanoma:

Melanomas at this stage have not spread to the lymph nodes or anywhere else in the body.

Stage 2 melanoma can be divided into:

Stage 2A: The melanoma is between 1.01mm and 2mm in thickness with ulceration OR between 2.01mm and 4mm without ulceration.

Stage 2B: The melanoma is between 2.01mm and 4mm in thickness with ulceration OR thicker than 4mm without ulceration.

Stage 2C: The melanoma is thicker than 4mm with ulceration.

Stage 3 melanoma:

² Abbreviated from MacMillan Cancer Support (2012) Staging and grading of melanoma. Retrieved 30th April, 2014, from MacMillan Cancer Support website
<http://www.macmillan.org.uk/Cancerinformation/Cancertypes/Melanoma/Symptomsanddiagnosis/Stagingandgrading.aspx>

Melanomas at this stage have spread to the lymph nodes or lymphatic tubes closest to the melanoma but not to anywhere else in the body. In stage 3 the thickness of the melanoma is not a factor, but the melanoma is usually thick.

Stage 3 melanoma is divided into stages 3A, 3B or 3C, depending on factors such as:

- the number of lymph nodes involved
- whether the lymph nodes contain melanoma cells that can be seen by the naked eye or only under a microscope
- Whether melanoma cells are found in the skin or lymphatic tubes near the melanoma.

Stage 4 melanoma

The melanoma has spread to distant areas of skin or distant lymph nodes, or to other organs such as the lung, liver or brain. This is called advanced or metastatic melanoma.

Breslow thickness

The most important measurement for melanoma is how thick (deep) it is. This is called the Breslow thickness (named after the doctor who introduced it). It's the distance in millimetres from the surface of the skin to the deepest melanoma cells.

Most people have melanomas that are 1mm thick or less - these are stage 1 melanomas. These are very unlikely to spread into the lymph nodes and most can be cured by a simple operation known as a wide local excision.

Thick melanomas are more likely to spread into the lymph nodes closest to the melanoma. If the melanoma has spread to the lymph nodes, additional surgery will be needed to remove the lymph nodes as well as the melanoma.

Melanoma in situ

Melanoma in situ (also known as melanocytic intraepithelial neoplasia, MIN) is a term used to describe the very earliest stage of melanoma. The melanoma cells are just in the very top layer of skin (epidermis) and haven't started to spread down into the dermis. Because the melanoma is only in the very top layer of skin, people with melanoma in situ do not usually have any risk of the melanoma spreading to other parts of the body

Content last reviewed: 1 February 2012

Appendix D. Confirmation of Coventry University ethical approval

TO WHOM IT MAY CONCERN

RRU/Ethics/Sponsorlet

Friday, 10 May 2013

Dear Sir/Madam

Researcher's name: Helen Mortimer
Project Reference:
Project Title: P11535

The lived experience of malignant melanoma: diagnosis,
treatment and beyond

The above named applicant has successfully completed the Coventry University Ethical Approval process and received authorisation for their project to proceed.

I should like to confirm that Coventry University is happy to act as the sole sponsor for this applicant and attach details of our Public Liability Insurance documentation.



Ian Marshall

Deputy Vice-Chancellor (Research)

Enc

Appendix E. Research Ethics Committee approval


Health Research Authority
NRES Committee West Midlands - Solihull
East Midlands REC
Centre The Old
Chapel Royal
Standard Place
Nottingham NG1 6FS

Telephone: 0115 8839435
Facsimile:

09 August 2013

Miss Helen Mortimer
Department of Clinical Psychology
James Starley Building, Coventry University
Priory Street, Coventry
CV1 5FB

Dear Miss Mortimer

Study title:	The lived experience of malignant melanoma: diagnosis, treatment and beyond
REC reference:	13/WM/0274
IRAS project ID:	126120

Thank you for your letter of 30 August 2013, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Assistant Co-ordinator, Leni Robson, NRESCommittee.WestMidlands-Solihull@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Evidence of insurance or indemnity	AON – August 2012	
Interview Schedules/Topic Guides	2	20 June 2013
Investigator CV	Miss Helen Mortimer	20 June 2013
Investigator CV	Dr Eve Knight	01 May 2012
Letter from Sponsor	Letter from Ian Marshall	10 May 2013
Other: Participant debrief Sheet	1	20 June 2013
Other: Demographic collection	24/06/2013	
Participant Consent Form	3	30 July 2013
Participant Information Sheet	4	07 August 2013
Protocol	2	15 May 2013
REC application	126120/467124/1/821	20 June 2013
Referees or other scientific critique report	Ethics Review Feedback Form	
Response to Request for Further Information	Letter from Helen Mortimer	30 July 2013

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

13/WM/0274

Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project. Yours sincerely



pp: Dr Rex J Polson
Chair

Email: NRESCommittee.WestMidlands-Solihull@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: Miss Helen Mortimer
Jo Williams, South Warwickshire General Hospitals Trust

Appendix F. Research & Development (R & D) approval

Research malignant melanoma REC ref: 13/WM/0274

Thu 22/08/2013 07:32

Dear Helen

Study Name: The lived experience of malignant melanoma: diagnosis
treatment and beyond

REC ref: 13/WM/0274

IRAS project No: 126120

Protocol Version: 2 Dated 15 May 2013

Thank you for your application for the above named study

I can confirm that following review the Trust is able to grant approval

Good luck in undertaking the study! We will look forward to hearing the outcome of
your study in due course

Should you require any further assistance at any time please do not hesitate to contact
me

Kind Regards

Jo

Jo Williams
Undergraduate Education & Research Manager
South Warwickshire NHS Foundation Trust
Room 3 Medical School Building
Lakin Road
Warwick
CV34 5BW

Phone: 01926 495321 extn. 4411

Mobile: 07785573430

Fax: 01926 600849

This email has been scanned for viruses; however we are unable to accept
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Warwickshire NHS Foundation Trust nor NHS Warwickshire unless explicitly
stated. If you have received this email in error please notify the sender.
The information contained in this email may be subject to public disclosure
under the NHS Code of Openness or the Freedom of Information Act 2000.

The conditions of this approval are as follows:

- 1) You adhere to the approved version of the protocol and notify R&D immediately of any changes to the study, including any new staff working on the project, who may require Trust or Honorary contracts issued.
- 2) You notify R&D immediately of any Serious Adverse Events, including Suspected Unexpected Serious Adverse Reactions (SUSARs)
- 3) You adhere to the requirements of the ethics committee as detailed in their approval letter and standard operating procedures which can be found on www.nres.npsa.nhs.uk
- 4) For CTIMP studies, you adhere to the regulations, including good clinical practice, of The Medicines for Human UK Clinical Regulations (SI 2004/1031; SI 2006/1928; SI 2006/294; SI 2008/941; SI 2009/1164; SI 2009/3063; and SI 2010/1882).
- 5) You notify R&D immediately of any Serious Breaches of GCP or the protocol occurring on this site. This applies to both sponsored and hosted projects. Guidance on Serious Breaches identification & reporting can be found at:
<http://www.mhra.gov.uk/Howweregulate/Medicines/Inspectionandstandards/GoodClinicalPractice/News/CON084915>
- 6) You adhere to the applicable R&D Standard Operating Procedures which can be found on <http://sharepoint/policies/default.aspx> under R&D
- 7) You notify R&D on completion of the project

The duration of this approval extends to the date specified in the IRAS ethics application form, except where action is taken to suspend or terminate the opinion or should your research not begin within 2 years of the approval date.

Pharmacy

Should your study require the dispensing of drugs, please do not commence work on the project until pharmacy has issued the green light, as per MHRA requirements (<http://www.mhra.gov.uk/Howweregulate/Medicines/Inspectionandstandards/GoodClinicalPractice/Frequentlyaskedquestions/index.htm>). The green light confirms that pharmacy has all procedures and documentation in place and can comply with the medicines management aspects of the study. The pharmacy team will email you the green light approval once the above is in place.

May I also draw your attention to the Research Governance Framework which can be found on the internet http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4108962 and remind you that all research within the Trust should be run to the standards as outlined in this document. Guidance and advice is always available from the Department of Research and Development should you require it at any stage of your project.

If you have any queries please do not hesitate to contact me.

Yours sincerely



Liz Adey
R&D Manager

Carbon Copy: Kate Martin

Version 10.0 May 2012

Appendix G. Semi-structured interview schedule

Interview protocol

Questions to be asked to all participants are in bold. Prompts below are available to be used by the researcher *if required* to assist the participant to tell their story or to elicit a greater depth of information

Can you tell me about your experience of melanoma?

General introductory question designed to be very open so to allow the participant to lead the interview with most salient information to them

Can you tell me about the diagnosis?

- What happened? When?
- Who was around when you received your diagnosis (personal and professional)?
- How did you feel
- How did you react to the diagnosis?

Next I'd like to hear about the treatment

- How was it?
- Thoughts and feelings about it?
- Impact of treatment?

Can you tell me about if or how your life was affected by having melanoma

- Family/relationships
- Practically/emotionally/spiritually
- Concerns or worries?
- If no change at all how do you understand that?
 - How do you feel about that?
- Sun behaviour?
- If life has been unaffected explore why this might be so

Can you tell me about how you coped with your experience?

- Who has helped – personally and professionally
- What have you done if/when times have been difficult
- What has helped you to keep going
- If don't feel like needed to cope, not had problem – explore this further

How do you feel about your experience now?

- Any positives to be drawn?
- What have been the toughest parts of your experience?
- What has helped you during your experience?
- How do you feel about the care that you have received?

If not covered already, enquire about melanoma site.

Is there anything else that you would like to share with me that we have not covered?

Appendix H. Participant information sheet

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D. CPsychol

THE UNIVERSITY OF
WARWICK



Participant information sheet

Title: The lived experience of malignant melanoma: diagnosis, treatment and beyond

Principal researcher: Helen Mortimer, Trainee Clinical Psychologist

You are being invited to participate in the above research study. This is an information sheet to provide you with what you may need to know to help you to decide whether you would like to participate. It will provide information about the nature of the research study and what will be involved if you do decide to take part. There are contact details available in this document if you have any further questions you would like to be answered.

Why have I been invited to participate?

You have been invited to participate as you have had a diagnosis of, and received treatment for, malignant melanoma. People who are attending follow up appointments at this service are being invited to participate.

What is the purpose of the study?

This is a study into the experiences of people who have had malignant melanoma. To date there has been little research which has attempted to gain an understanding of the experiences of people who have had malignant melanoma, from their own perspective. This is the overall aim of this research.

It is hoped that this study may help clinicians to understand more the impact of diagnosis and treatment for people with malignant melanoma, and their experiences of adjusting to this. Findings from the study may inform future practice and guide further research and support for people who have had this diagnosis.

Do I have to take part?

No. Choosing to take part in this study is voluntary. Choosing not to take part will in no way affect the care or treatment that you receive.

Dean of Faculty of Health and Life Sciences

Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

The lived experience of malignant melanoma; Participant information sheet; 7/8/13; v4
Professor James Tresilian BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7657 3009

www.coventry.ac.uk

What do I have to do?

This is an interview based study and will involve meeting with the researcher to talk about your experiences at an agreed convenient location. The interview will be digitally recorded, however all information will be treated as confidential and you will not be identifiable in any published findings. You will be asked to consent to being interviewed, digitally recorded and the audio tape being used for the research. You will need to supply some basic demographic details, and talk about your experiences with the researcher. The interview will last approximately 60 minutes in duration depending on how much you wish to talk. The entire session including completing consent forms, personal information and the interview itself will last around 90 minutes.

The interview will focus on your experience of having malignant melanoma. It is a chance for you to share your thoughts and feelings about this experience. Every care will be taken to minimise distress and you can choose what to share. At the end of the interview you will receive contact details of sources of support that are available.

What are the benefits and disadvantages of taking part?

We cannot promise that the study will help you but the information we get from this study may help improve the experiences of other people who have malignant melanoma. The interview also provides a chance for you to tell your story and add to the research in this field. Some people may find this to be a rewarding or distressing experience, but it is entirely up to you what and how much information you choose to share with me. You can choose to pause the interview or withdraw from the interview without giving a reason at any point. If you require further support following an interview this will be available to you through your existing care team, or, if necessary a referral to a clinical psychologist can be made.

What if I agree to take part and then wish to withdraw from the study?

After the interview there will be two weeks in which you will be able to withdraw from the study, without giving a reason and without it affecting your medical care. This can be done by contacting me via contact details provided.

Will my participation in the study and data be kept confidential?

Yes. Audio taped and demographic data will be stored securely in locked premises. Codes or pseudonyms will be used instead of names in order to protect your anonymity. All information which is collected about you during the course of the research will be kept strictly confidential. Some parts of this data may be looked at by authorised persons from the University or representatives of regulatory

The lived experience of malignant melanoma; Participant information sheet; 7/8/13; v4

authorities to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant. The information you give as part of the research process will be analysed and used only as part of this study. Confidentiality may only be broken if the researcher is concerned regarding you or someone else coming to harm. In this instance your GP, care team, or criminal services may be contacted. This is rarely necessary and we would always endeavour to speak to you about these concerns before breaking confidentiality. When the study is completed data generated by the study will be stored in a confidential place at Coventry University for five years and then destroyed.

What will happen to the results of the research study?

It is intended for the results of the study to be published on its completion in September 2014. You will not be identified in any report/publication. All participants will be able to receive a summary of the results. At the end of the research study you will receive no further contact from the researchers.

Who is organising/funding the research?

The research is in collaboration with the Universities of Coventry and Warwick, and the NHS. This research is supported and supervised by Dr Eve Knight, Clinical Psychologist and Dr. Kate Martin, Clinical Psychologist

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been approved by the Solihull NHS Research Ethics Committee, Coventry University Ethics Committee and has been registered with the hospitals' Research and Development (R&D) departments.

What if I have any questions or concerns?

For further information or concerns you may have about any aspect of the study or participating you can contact me, the researcher using the contact details below, who will do my best to answer your questions. The Patient Advice and Liaison Service (PALS) can offer independent advice on participating in research. They may be contacted at Solihull hospital on 0121 424 1212 or Warwick hospital on 01926 600 054.

What do I do now?

If you are interested in taking part in the research or in finding out more about it, I would be grateful if you could complete the enclosed contact form and return it in the pre-paid envelope provided. You will then be contacted by me, Helen Mortimer, in order to set up an interview time and date. If you have any further questions about the study please do not hesitate to contact me. Allowing me to contact you about the study does not mean that you are obliged to take part.

Thank you for your time,

Helen Mortimer
Trainee Clinical Psychologist

Contact details:

Email: mortimeh@uni.coventry.ac.uk
Tel: 02476 887806

Appendix I. Participant response sheet

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D. CPsychol



Participant Response Sheet

I have received the Study information pack and read the participant information sheet.

I would / would not (delete as applicable) be interested in being a participant in this research and would like some further information regarding this.

Please provide details for contact:

Telephone

Email

Please indicate if you have a preferred means of contact and time of contact below

.....
.....

Dean of Faculty of Health and Life Sciences

Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

Head of Department of Psychology

Professor James Trellian BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7657 3009

The lived experience of malignant melanoma; Participant response sheet; 20/06/2013; v1

www.coventry.ac.uk

Appendix J. Participant consent form

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D. CPsychol



Participant Consent Form

Title of Study: The lived experience of malignant melanoma: diagnosis, treatment and beyond

Name of Main Researcher: Helen Mortimer

Please initial box

1. I confirm that I have read and understood the information sheet
for the above study.
2. I have had the opportunity to consider the information, ask questions and
these have been answered satisfactorily.
3. I understand that my participation is voluntary and that I am free to
withdraw from the interview at any time. I will have two weeks following
the interview to consider my participation and withdraw from the study
during this time. I will not need to give a reason, and my care will be in no
way affected. To withdraw my consent I can contact the researcher directly
via the contact details provided on the information sheet.
4. I consent to the interview being digitally recorded.

☐☐☐☐

Dean of Faculty of Health and Life Sciences
Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805
The lived experience of malignant melanoma; Participant consent form; 30/07/13; v3
Professor James Tresilian BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7657 3009

www.coventry.ac.uk

5. I agree to take part in the above study.

☐

Name of Participant

Date

Signature

Name of Researcher

Date

Signature

Participant K. Participant de-briefing information sheet

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D. CPsychol

THE UNIVERSITY OF
WARWICK



Debrief Sheet

Re: The lived experience of malignant melanoma: diagnosis, treatment and beyond

Thank you for your participation in the above study.

If you have any questions or concerns regarding your participation please contact me on 02476 887806 I will be happy to discuss these further with you.

If you feel that, as a result of the study or from issues arisen from the interview, you require further help or support please speak with professionals involved in your care or your GP who will guide you with this.

Below are some websites which you may find useful.

www.macmillan.org.uk

www.cancerresearchuk.org/skincancer

www.maggiescentres.org/Cancer-Help

If you have indicated that you would like to receive a summary of the research findings these will be forwarded to you at the address you have provided in due course.

Dean of Faculty of Health and Life Sciences
Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805
The lived experience of malignant melanoma; Participant debrief sheet; 20/06/13; v1
Professor James Tresilian BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7657 3009

www.coventry.ac.uk

Appendix L. The stages of IPA

Analytic stages for IPA (Smith, Flowers and Larkin 2009)

1	Reading and re-reading. The analyst immerses herself in the data and in particular in the participant's experience
2	Initial noting. Detailed, comprehensive exploratory notes are made. Engagement with the transcript is furthered
3	Developing emergent themes. The analyst uses her detailed notes to consider themes. These will reflect closely the participant's inner world but also the researcher's interpretation. The aim is to capture and reflect an understanding of the participant's experience.
4	Searching for connections across emergent themes. The researcher begins to map how themes may fit together
5	Moving to the next case The analyst focuses on the next participants transcript without bias from the previous and repeats the initial stages
6	Looking for patterns across cases

Appendix M. Excerpt of participant transcript with initial IPA coding

4

119 you get to my age and you've had all sorts of things and nothing
 120 seems to bother you, you expect it really don't you as you get older.
 121 I: so when you went to the hospital and had your diagnosis were
 122 you on your own or did you take your husband?

123 L: no, I had my husband with me, they made sure he came in with
 124 me and he always does anyway except that sometimes if I've gone
 125 back just for a check-up he perhaps has gone for a coffee or
 126 something but he always comes with me, we always do the hospitals
 127 together, and for him too

128 I: and what was that like, when you received the diagnosis?

129 L: well I was a bit shocked because what I thought they would do
 130 was the same as with my sister and it would be like a rodent ulcer
 131 and they would take the top off it, that's what I thought they would
 132 do but when she said no, I'm going to cut it out, that didn't bother
 133 me, I thought "good, get rid of it" you know, if there's a problem
 134 there take it out. But it was a bit of a shock as I was going back
 135 expecting her to say you know, everything was fine and we don't
 136 want to see you again, so, yes, and when I came out I remember
 137 saying to my husband when we came out because we talk about
 138 this, he's got lots of problems and we talk about if I go first and if
 139 you go first, and I said to him well it looks as if I'm on the cards, I
 140 could go first, but, it was all fine.

141 I: yeah, was that something that did weigh on your mind?

142 L: I think that I was just so grateful that they did it in two weeks
 143 because you are thinking all the time well if that's still growing so
 144 when it came just over the two weeks I was really, delighted with
 145 that. And er,

146 I: yes you just wanted it....

147 L: and it was a bit disappointing that the flap died and went black

148 I: so what was the story with that?

149 L: well he sort of cut the hole out and he cut down and along like
 150 two flaps, one going that way and one going this way and he pulled
 151 it over and joined the flaps

152 I: and then it went black?

153 L: yes, when I went back for the first check up the nurse noticed that
 154 there was a little bubble on the top and er, she said show it your
 155 doctor in about 4 days time so I went back in 4 days, Friday to the

any it in her shade expected as part of getting old.

made sure husband there - looking out for her. Doing everything with husband. A shared experience

Shocked more around the procedure than idea of cancer. Glad to bend matter of fact - Mortality - might be her. What goes first. Idea is could mean death. Grateful speed as good thing

long but disappointing. Ain't at all like nothing. description of procedure sounds unpleasant. Fond in matter of fact way. Next worry in the healing. Nurse noticed it. Following nurse advice

Just a part of getting older

Doing everything with husband

dealing in matter of fact way

expectation it would be fine

Shared experience with husband

Mortality

Grateful for speed. pleased positive language

Matter of fact

4

156 Wednesday, went back on the Wednesday and it was it had gone
157 black on the corner and she immediately rang F (surgeon), or the
158 secretary and she couldn't get through so she asked me to ring and
159 get to see him as soon as possible so he did see me the next day and
160 he said to shower regularly he gave me some iodine dressings, wash
161 it every morning and put this io- so I had to put dressings on it and
162 er go to the nurse, the district nurse at the doctors twice a week, so
163 they looked after it then, twice a week, and then when I eventually
164 went back, which was I suppose about 6 weeks afterwards and saw
165 Dr F, he, this flap had gone all round and it was just very loose blob
166 and gungey underneath so he actually took that flap off and that
167 was such a relief because I knew myself that there was nothing
168 getting under there properly, I was putting the dressing on the top
169 but it was a dry piece of dead skin that was preventing it going
170 underneath so I was delighted when he showed me, when he said
171 I'll take that off and then I started to use a cream and erm, fill it in
172 because it was quite a hole and I went to the nurses twice a week
173 but I had got to do it every morning myself so I showered it, washed
174 it well and erm, used the steroid dressing after to dry it out then put
175 this cream in and put a dressing on. So I did that every day for a few
176 weeks
177 *graphic? (or is this me being surprised)*
178 **I: and the treatment, as I understand it the first time, she removed**
179 **the, was it a mole?**
180 **L: it was different to a mole**
181 **L: the first apt she removed that and send it off for the biopsy?**
182 **L: yeah, you have to do 6mm or something so she did that and put 6**
183 **stitches in it and er, that was sort of 3 weeks later I knew it was a**
184 **melanoma. Spreading. And then 3 weeks after, two and a half weeks**
185 **I: and how did you find the treatment? Was it what you were**
186 **expecting?**
187 **L: well I had to go in for 12 o'clock and I didn't go in to theatre until**
188 **6 o'clock in the evening so I hadn't eaten anything and your just sort**
189 **of sitting there waiting, that sent my blood pressure up apparently**
190 **they said my blood pressure had been up all the time I had been**
191 **there, so I didn't feel nervous, I didn't think I was nervous, and then**
192 **we went upstairs to the theatre and they were very nice and er, I**
193 **was apparently the first, huh! so I don't know how that worked out**
194 **if I was the first one in the theatre, if they were doing all the others**
195 **in the clinic room? so that went well. I had a little nurse sitting there**
196 **whilst I was lying down here talking to me and telling me that...**

practical,
pragmatic
approach

Caring for the
wound.

Pleased with
treatment -
optimistic/
positive

epidemic is spreading.
Or is this just
what he knows
it as?

not eager
 sitting waiting
 blood pressure
 went up.
 Didn't feel nervous
 nervous about
 process - ~~the~~ she
 isn't ^{so} upset
 nurse sitting wait
 here, talking
 to her.

Not a problem
 Curious
 Worrying
 Can't.
 Long description
 of procedure.
 Bleeding
 oozing but
 stopped.
 Sense that she
 knows herself
 her body and
 back.
 Able to get
 round ok.
 Difficult to
 rest - it - couldn't
 put down
 Impact on
 arthritis near
 troublesome.
 Melanoma surgery
 not a problem but
 impact on arthritis

197 I: so it was a local anaesthetic?
 198 L: yes, and that wasn't a problem and I asked the nurse if I could
 199 have a look when they had finished and I saw the nurse who was
 200 down by leg going *shakes head* "no" so when I came out it was all
 201 well packed but I was able to walk to the car, that bled quite a bit
 202 through bandages but they said if it continued to bleed then I was to
 203 go to an A and E, which it didn't it seemed to stop and dry out so I
 204 didn't do anything about that until I went back to see the nurse
 205 which was a week later, so that's when she saw that it was dry on
 206 the top, but she wasn't, she poo-pooed it she said "oh no that's
 207 fine, just see your doctor in 5 days" so I wish I had gone before that.
 208 But never-the-less these things happen don't they? *these things happen!*
 209 I: so you were able to walk out of the hospital but it did it affect
 210 you after that?
 211 L: I was able to get round normally. They said, you know, rest it but I
 212 mean my chairs have all got these (recliners) on them. But you
 213 couldn't rest it cos you couldn't bare it down and I was lying like this
 214 all the while (twisted) if I was resting it which meant that I've got
 215 arthritis in my hip and my back and mu knew and my hip played up
 216 terrible and I couldn't go to my swimming so that was my biggest
 217 problem because of not having the exercises I suffered with my hip
 218 and my back
 219 I: oh so the swimming helps with your arthritis?
 220 L: that's right, so yeah, that was the biggest problem of pain wise,
 221 my hips
 222 I: so not the pain of the surgery but the impact on your hips
 223 L: yes, yes (pause)
 224 I: so you said that you felt you didn't have much to say because
 225 you weren't
 226 L: I weren't worried about it,
 227 I: yeah, you weren't worried about it and you feel that you've
 228 coped well with it? I don't know if you, how you make sense of
 229 that, how you have coped so well with it?
 230 L: well when I was 29 I had the hysterectomy and that was, it was
 231 self-multiplying cervical cancer so they said that was a different type
 232 of cancer as I said at the time would I get cancer anywhere else and
 233 they said not from this because it's just an individual cancer and er, I
 234 don't know, with all these moles I thought, and with my sister

I was it
 in her smile
 Curious
 Worrying to
 be involved
 Impact upon
 arthritis -
 most troublesome
 Role of
 previous
 experience
 with
 cancer?

Has had
 cancer before
 knew that
 lots of moles
 & chances.

6

235 having skin cancer I thought I've got to keep my eye on these moles
 236 because one day one of these could go peculiar so you know that
 237 was in the back of my mind so it wasn't really a shock as such and
 238 you know that you can have them removed it isn't like breast cancer
 239 or anything like that where you can, it must be terrible because you
 240 know it can be ongoing and I know this can re-occur somewhere
 241 else so this is why we have to keep a look out but then that's no
 242 problem, to be aware

243 I: perhaps you had some sort of preparation, you had thought it
 244 could happen

245 L: yeah, that's right yeah., And I'd had motorbike accident and I had
 246 seen my sister have this skin graft and I already had a skin graft on
 247 my leg and erm, you know that wasn't new to me so

248 I: you had more experience of similar thing

249 L: yeah, I had had an insight. At the motorbike accident, my, the boy
 250 was killed so that was quite traumatic at 17 so and er, I had a baby
 251 that died four days old and so I've had to sort of really, I've had TB
 252 and I was in the sanatorium, for 6 months, so you know? You think
 253 whatever life dishes out with you you have got to get on with it,
 254 suppose I'm a bit hard in that respect.

255 I: is there anything else you could say has helped you? Family,
 256 friends, professionals that type of thing?

257 L: well I don't like to be a nuisance to professionals. I think they've
 258 got enough to do haven't they. My family has been very good, I've
 259 got two sons and their wives have been very good er, the other
 260 thing that I've found is that I've had to sort of say to them is that it's
 261 going to take a while to heal and it's alright so don't keep asking me
 262 because they would phone saying how are you, we've got a lot of
 263 people, I go to church and people in the church and in the group and
 264 every 5 minutes you're sort of, they're wanting a running
 265 commentary on how you are getting on which is lovely but to keep
 266 on... I wanted to forget it, I wanted to just get the dressings off and
 267 let it heal

268 I: so their good intention...

269 L: making an ordeal of it really when it wasn't

270 I: okay so perhaps other people could be

271 L: it was probably something new to them wasn't it, yeah, so they
 272 were all really good and my friends were good and I kept and I do

better than
breast
cancer!

Other life
events.

All in
perspective?

Too much
concern?
just
wants to
get on

knows her
sister having
skin cancer
she's been
treated for
breast cancer
not a problem to
be aware of
re-occurrence
already had
skin graft -
so that's not
a new experience
either

previous
trauma that
she has dealt
with
deal with
what life gives
you
the experience
nothing in
company or
Doesn't like to
be a nuisance
to professionals
Not wanting to
put on them
Support from
Family
Others' concern
needing to be
kept in check -
not wanting to
dwell on it

Then thinking
it's an ordeal,
her not - just
getting on
with it.

Family + friends
good.
F+F not as used to dealing
with it as she was.

Appendix N. Super-ordinate and sub-ordinate themes for one participant

1. Shock at diagnosis
 - Cancer!?!?!?
 - Never thought it would be anything
 - Thoughts of death
2. It was bad.... but there are worse things
 - Severity of the surgery
 - A hard time, melanoma not the worst part
 - In the context of other health conditions
3. Finding the positive, fighting the negatives
 - It could be worse
 - Being positive
 - Seeking to maintain a sense of reality
 - Laughing and finding fun
4. Moving on
 - A chapter closed
 - Practical, necessary behavioural changes
 - Changes to feelings of immunity
 - Another thing over come – an achievement!
 - “expert” mole checker